
Subject: More About ME

Posted by [jmeadows](#) on Fri, 11 May 2012 00:40:47 GMT

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More About ME

Subject: Re: More About ME

Posted by [SarahAllegra](#) on Fri, 11 May 2012 00:56:32 GMT

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As someone with ME/CFS (as they insist on calling it in the US) this is an intensely interesting topic for me. I enjoyed the articles posted, and, well, thought I'd include this link to another article: <http://www.scholarsandrogues.com/2012/03/25/artsunday-using-photography-to-cope-with-chronic-fatigue-syndrome/>

Full disclosure, I wrote this article. But it's a true and accurate representation of my experience living with ME (which is also a comparatively mild case, as depressing as that is to think of). Since there seem to be relatively few people wanting to talk about what a real and awful illness it is, I try and do what I can to raise awareness about it through my art work and writing articles and whatnot.

I believe Robin has said before what great motivators animals (and especially dogs) are when you're feeling like a cold sack of poo; this is very true. There's nothing like a soft pair of eyes staring sweetly, but insistently at you to find the strength you didn't think you had. Forced exercise is the devil. But having a four-legged hound to make you walk every day is very helpful. Not to mention how helpful their snuggles and kisses are.

Subject: Re: More About ME

Posted by [claning](#) on Fri, 11 May 2012 01:43:51 GMT

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Mostly just to say Amen! Hallelujah! Sing it, sister!

I have a "mild" (thank goodness) case of fibromyalgia, and I can relate to everything you're saying.

My own bad reactions to innocent unsuspecting food are mostly to any form of meat or poultry (even chicken broth). I started out being a vegetarian by choice in my 20's but my body clearly agrees with me that this was a good idea. Since I have enthusiastic carnivores for friends, this

does make me hard to feed.

I'm currently fighting back to normal from a painful Monday and Tuesday -- trying to be careful not to do too much. I agree that it's vitally important to exercise right up to your personal limit (but not over it) and I do know someone who has managed to regain considerable function that way. The trouble is, I find it's hard to judge how much is too much, because the feedback (ouch!) is usually delayed anywhere between 12 to 24 hours. So it's always tempting to do just a little less than I can, because I'm trying to avoid waking up tomorrow morning feeling like I've been run over by a truck.

Subject: Re: More About ME

Posted by [Annagail](#) on Fri, 11 May 2012 02:29:16 GMT

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I have nothing but respect for all you folks out there who have to deal with a chronic illness. I know a little bit of what you mean by doing all you can physically but not a nanometer more- I'm presently laid up with a Level 3 ankle sprain (read: OWW) and just had to go back on crutches from doing too much. Doing too much in this case meant doing normal errands using my "boot" (removable castlike stabilizer thingy) without crutches and limping from the bedroom to the restroom without it. And I couldn't tell I was doing too much till several days afterwards, when my pain levels started going up instead of down.

I hate being laid up, I don't want to go grocery shopping with the electric cart-thingy and I hate taking forever to do anything. And I hate having to decide what chore or what errand I'm going to do today. I can't cook a whole meal- I can cook one dish as long as it's not terribly labor intensive. I can run one errand if I can find a close parking spot. I can go to a friend's party if I don't have to crutch too far and if there's somewhere to sit and put my leg up at said party. Going to a bar is Right Out. And I still don't know if I'm doing too much or if my pain levels are going to start spiking on Sunday.

I don't know how you guys do it. Much respect and admiration to everybody who deals with anything chronic.

Subject: Re: More About ME

Posted by [Joseph-ine](#) on Fri, 11 May 2012 04:10:10 GMT

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As one of the fortunates who doesn't suffer from ME, I just thought I would throw in my support for the use of vitamins (and minerals come to that).

I was turned onto magnesium by a friend who regularly doses her horse (I know - odd way about it). I knew vaguely that its needed for muscles etc, but I hadn't realised it was also important for nervous tension, stress etc. After having quite a recent stress related sleep problem, I carefully tried adding small magnesium supplements to my diet - specifically close to bed time. Now I don't know if its the magnesium alone, or the combination of magnesium, valerian, calm time reading prior to sleeping, but lately I have started hitting a point where my body suddenly says: "now sleep!!" at a reasonable time and it does, because I literally cannot keep my eyes open. Its such a relief!

However I do realise it doesn't always work for everyone (too much magnesium is not a good thing for the digestive system) and I will be talking to my doctor about it, because last time I self dosed myself, I ended up finding out later that (the iron supplements I had been taking) were making me sicker. It turned out that I had haemochromatosis - and definitely did not need more iron! I am lucky my doctor diagnosed me at an early age, because had I found out later in life it could have been rather disastrous. Anyway, there is still a lot to be said for supporting our health with vitamins and minerals providing we get sound advice about it.

Subject: Re: More About ME

Posted by [ravenandrose](#) on Fri, 11 May 2012 04:55:40 GMT

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Robin,

Thank you so much for writing about this. As sorry as I am that other folks deal with this too, it helps to know I'm not alone.

People who mention forced exercise as the thing that would solve my problems are very lucky I am a mild mannered individual. Even though I am (almost) sure they are all well-meaning folks.

But, it's a very good point about using energy up to your limits. Well said.

Magnesium is a big deal for me too. One of the pieces of the puzzle.

Subject: Re: More About ME

Posted by [Diane in MN](#) on Fri, 11 May 2012 05:29:20 GMT

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I have nothing but admiration for people who can live gracefully with chronic illness, especially poorly-understood chronic illness. Bravo to all, and may the researchers start coming up with

some consistent answers.

Subject: Re: More About ME

Posted by [Firebyrd](#) on Fri, 11 May 2012 06:57:21 GMT

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Robin,

I'm always very thankful when you make posts like this. While I wouldn't wish this on anyone, it's nice to not feel so alone in what I'm experiencing. When I was first diagnosed, I participated in some support communities quite a bit, but the sheer amount of hearing about all the crap from doctors, family, friends, and symptoms was just too much for me and made me very depressed. Your posts help me feel like I'm not insane or a malingerer without weighing me down with the hopelessness of not only my own inability to get the professional help I need but that of so many other people as well.

I also appreciate the livejournal link. I hadn't encountered someone else before who had trouble comprehending language sometimes and it's so good to know I'm not alone! It's bizarre, I'll hear someone say something, but it's complete gibberish. It often takes a few seconds (by which point I've said, "Huh?" and made myself look like an idiot), and then it's like something snaps into place and my brain finally sorts things out and presents the meaning of what I just heard.

Subject: Re: More About ME

Posted by [holmes44](#) on Fri, 11 May 2012 10:40:47 GMT

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Firebyrd wrote on Fri, 11 May 2012 02:57Robin,

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I've said, "Huh?" and made myself look like an idiot), and then it's like something snaps into place and my brain finally sorts things out and presents the meaning of what I just heard.

the same here.the 2 second delay before it hits your brain is the worst feeling.

Subject: Re: More About ME

Posted by [Birdreader](#) on Fri, 11 May 2012 13:58:00 GMT

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I would like to add a sincere prayer that all of the positive enery of sharing the stories send a comforting energy boost to all.

Subject: Re: More About ME

Posted by [Black Bear](#) on Fri, 11 May 2012 13:58:24 GMT

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I think you've put your finger on it, about people trying to close the gap forged by illness--any illness, really. People generally don't say quite such stupid stuff about things like chronic asthma, probably because it's more common and people "know" what the word asthma means... but there's still often a kneejerk reaction to just say something like "oh my brother has that" or "do you swim? I hear asthmatics are really good at swimming!" I figure it's just that people want to say something to close that gap, and connecting their own experience/knowledge/lack thereof up with what you've just said is a way to do that.

As you've mentioned depression, I thought I'd throw in the fact that exercise is often recommended as a treatment for depression--and that for people who don't have personal knowledge of either one, CFS and depression appear in some ways symptomatically similar. This may lead to a sort of blanket assumption that exercise is a good approach to coping with CFS. Emphasizing the clear distinctions between the two is important, because they're NOT the same thing, as Robin rightly points out.

Subject: Re: More About ME

Posted by [Firebyrd](#) on Fri, 11 May 2012 17:48:56 GMT

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Black Bear wrote on Fri, 11 May 2012 07:58

As you've mentioned depression, I thought I'd throw in the fact that exercise is often

recommended as a treatment for depression--and that for people who don't have personal knowledge of either one, CFS and depression appear in some ways symptomatically similar. This may lead to a sort of blanket assumption that exercise is a good approach to coping with CFS. Emphasizing the clear distinctions between the two is important, because they're NOT the same thing, as Robin rightly points out.

Unfortunately, Black Bear, in my experience, the exercise thing usually comes from medical "professionals." Over and over and over. And when I tell them that I've tried, multiple times, and ended up in worse shape with horrible pain resulting for a minimum of six months afterwards, they nod, smile, and say, "Oh, well you have to work up to it." As if I don't know and didn't do that! They /should/ know better, but they often refuse to even acknowledge that things like ME/CFS and fibromyalgia exist, so of course they're hardly going to keep up with what effective treatments actually are.

Subject: Re: More About ME
Posted by [Black Bear](#) on Fri, 11 May 2012 19:26:06 GMT
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I was talking specifically about the "well-meaning individuals" making unwanted suggestions issue; obviously the problem of doctors who don't listen to what their patients are telling them is a whole 'nother ball of wax!

Subject: Re: More About ME
Posted by [shalea](#) on Sat, 12 May 2012 01:36:48 GMT
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Black Bear wrote on Fri, 11 May 2012 09:58As you've mentioned depression, I thought I'd throw in the fact that exercise is often recommended as a treatment for depression...

From personal experience with depression, exercise is actually quite useful in keeping a balance once you've dragged yourself up out of the hole. From further personal experience, I can say that the problem is the dragging out of the hole. I've found that even the sincere fourleg isn't always enough to drag you out the door for more than just a plodding amble around the yard to allow said fourleg to do his business outside.

Depression is very much a disease of the brain, but at least with it doctors (in my experience) tend to know that the problem is some imbalance of the brain chemistry and not laziness or personal weakness.

Subject: Re: More About ME

Posted by [Black Bear](#) on Sat, 12 May 2012 13:41:30 GMT

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Yes--I don't want to threadjack this to depression; but as someone who has chronic depression issues but not CFS, I agree that the hump is getting TO the exercise. But exercise has been as close to a temporary cure for depression as it gets, when I do it. :)

Subject: Re: More About ME

Posted by [oldoakforest](#) on Sun, 13 May 2012 14:01:02 GMT

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Some of the issue is that medical professionals don't always want to admit that they know too little about a particular disease to help. I think the true sign of a good GP is a willingness to admit that s/he doesn't know much about a particular disease. One of my friends is a first year medical student (I'm in the UK, but she's doing the course as a graduate), and the sheer amount of 'stuff' they need to learn just to become basically competent doctors is impressive. The rarer diseases, such as ME and my own demon, anorexia, seem to be covered in minimal depth so that even doctors can come out with completely rubbish views on these diseases (for the record, the correct response to a request for referral to the eating disorders unit is NOT 'So you haven't eaten today, then?').

A good doctor, however, will admit ignorance and at least make an effort to be sensitive before working with you to find the best way to support you.

Unfortunately, good doctors for one's particular disease can be tricky to find.

Also, on the topic of supplements: when I was first diagnosed with anorexia, I was severely constipated and one of the few treatments that actually worked was, in fact, high doses of magnesium! What would be an undesired consequence for most people in my case was precisely the desired outcome.

Subject: Re: More About ME

Posted by [sarahkay](#) on Mon, 14 May 2012 16:13:19 GMT

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I just want to say how grateful I am to Robin for pointing out that even though people often say stupid things it's important to recognize that they're trying. I have been trying to train myself to remember this so that every time I have to tell someone new about my illness I don't get so angry and offended. I have celiac disease (which was a nightmare to diagnose properly) and have been gluten free for about three years and have been feeling like myself again just these last six

months, although I still have trouble digesting dairy. While on the road to recovery I wrote this miniature "guide" based on how people had treated me since I discovered my illness. It was written with some bitterness but also humor; I hope there will be those who can relate. As food permeates all aspects of our lives and is part of every family gathering, social event and celebration, my illness is a huge stresser for me when it involves other people, and learning how to deal with the people is a huge part of learning how to deal with my illness. I am happy to report that now that I am feeling better physically, I'm able to cope better mentally with the stupid things people regularly say and do. :)

What NOT to say/do to your friend/family member with a severe food allergy/intolerance...

- tell them how grateful you are that you and your children don't have to deal with such things
- bring home food they can't have and remind them that they can't have any
- eat something delicious that they can't have and, while relishing it with exaggerated pleasure, tell them how horribly disgusting it is and that they wouldn't want any
- pretend that you don't know or have forgotten their food issue, offer them something they can't have, then laugh at how good your joke fooled them into thinking you were only being cruel out of ignorance.
- invite them over for dinner, then complain about how hard it was to cook for you
- invite them over for Thanksgiving, then make a list of all the dishes you absolutely cannot change to accommodate their medical needs, because tradition is more important than inclusion
- promise that you will use up and get rid of all the food they can't eat and replace it with safe food for them--then don't
- say that you are going to make a special, separate batch of something safe for them to eat, then don't, and lie about it, thinking that what they don't know can't hurt them
- demand that they share their more expensive, difficult to make treats with you and everyone else not on a special diet, even though you have plenty of other options and can't share any regular treats with them
- hand out special treats to everyone but them because you figured they were used to being left out anyway
- promise to keep a special section of the kitchen clean and safe fro them, then persist in bending and breaking the rules to suit your lifestyle and needs, making the entire effort moot

-complain loudly, and often, about how their diet is frustrating and inconvenient and annoying to you. Don't give a thought to how it might be even more frustrating, inconvenient, and annoying to them, especially when dealing with people like you is part of it

Subject: Re: More About ME

Posted by [Birdreader](#) on Mon, 14 May 2012 16:25:43 GMT

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I emphasize with you totally. Sounds a lot like my family. (I have egg, dairy, bran, corn, and garlic as my main food allergies) The only person who really understands is my sister who shares some of the allergies. Very frustrating. I hope you have found all of the good substitutes.
