

Testimony

Jennifer "Nonna" Buckley

To whom it may concern,

My name is Jennifer "Nonna" Buckley, and I am a CFS patient. As a young girl I was diagnosed with Fibromyalgia, but had it pretty much under control during my teenage years with regular gentle exercise... I used to be able to walk miles on the hiking trails near our home. Then, when I was seventeen, I went to college in a different state and came down with a "flu-bug" during my first term. I saw the school nurse who sent me home and told me to wait it out... like anyone would have - afterall there isn't much you can do about a flu virus but rest and increase your fluids. Unfortunately, I just didn't get better. My husband and I ended up returning to my parents' home hoping I would improve there... and over time I did. But I never returned to my normal state of health. I saw a doctor briefly who said I might have CFS, but I was probably just depressed... I was really touchy about doctors thinking I might just be "crazy" from my childhood, so I chose to ignore my symptoms and go about my life as normal.

As the years passed, any type of stressor - whether good or bad - would cause a flare up of these horrible flu like symptoms... I would spike a fever, and my throat would be full of ulcers... literal holes in the lining. The muscle aches I chose to ignore as long as I could since I was used to pain from the Fibro... but then 6 years ago I noticed I didn't just hurt anymore -- now I was unbelievably weak. Pushing a vaccum cleaner became the stuff work outs are made of. Right around that same time I took a terrible fall down a flight of 16 stairs... it was just before my 26th birthday. When I "got up" from that fall, my entire right side was significantly weaker than the left... even my right eye drooped. I spent my 26th birthday in an MRI tube expecting to hear bad news... What I heard was even worse... "There's nothing wrong with you. You're neurons are just too pooped to pop." (That's exactly what the neurologist said to me - verbatim.) So I was sitting there with my right eye drooping, unable to balance, shuffling around like an 80 year old, and there was nothing wrong? I was the mother of 2 young boys - both on the autistic spectrum - I didn't have time in my life for nonsense. I went home and spent about two weeks in bed figuring I just needed to rest my "neurons" and I could go back to my normal life - my mother came and helped with our boys.

After those two weeks I did improve a bit... I wasn't as "droopy" and was quite happy to at least look normal again. But any time I became tired or stressed out - I would "relapse". I tried returning to the neurologist, but he continued to tell me there was nothing wrong... and finally offered to botox my eye! That was the last time I saw him. A little over a year ago - the January of 2010 I began to notice severe memory problems. Not just the fog that I was used to - but scary things - walking into the kitchen to do the dishes, and discovering the sink empty. Reaching for a glass to put it away - and discovering it already in the cupboard. Walking over to turn off an outside light - and discovering it already off... All sorts of things that needed to be done, that I was the only one around to do - finding them already done with no memory at all of doing them... not even a wispy, faded one. I was scared, and I began seriously looking for help. I went to a different doctor - someone who I knew at least understood Fibromyalgia, and he did a complete and intense blood workup and other tests to rule out all sorts of things. He diagnosed me with CFS (and also discovered my thyroid issues not uncommon in people with CFS). Over this last year of treatment I have had some improvement, but it looks like I've been sick so long

I'll never get back to "normal" - I'm thankful that I can at least look in the mirror now and not have the face of a "stroke victim" looking back at me unless I've really "over-done" things.

Unfortunately, I've continued to have body systems try to shut down on me... most recently my doctor had to send me to a cardiologist who diagnosed me with Autonomic Nervous System Dysfunction and discovered I have developed a prolapsed valve. Things are now very complicated as my body has a hard time regulating my blood pressure - it drops and doesn't like to return to "normal" - which is hard on my heart. Sometimes I'll be standing or walking and just pass out from my blood pressure falling. This "Dysautonomia" is not unheard of in CFS/ME patients... but it is hard to treat. I am extremely sensitive to chemicals of any kind, so medication isn't really an option at this point... perhaps I will improve enough in the future that we'll find one that will work. I waver back and forth between hope and discouragement, and try not to think about all that seems to have been taken from me. It's hard to raise my boys knowing that they don't really remember a time when mom wasn't sick - and I worry about what would happen to them if something happened to me - autism (even high functioning autism) makes life really hard if you don't have someone there to help you. I hate the thought of leaving my husband alone in all this... I've hated having to watch him watch me suffer, and be unable to do anything about it. My prayer is that doctors will begin to take this disease seriously, and researchers will find answers...

Last August I wrote a post on my blog trying to explain what this illness is like to live with day to day... I would appreciate it if my testimony, or at least the following description of what my life is like as a CFS patient, could be shared with the Chronic Fatigue Syndrome Advisory Committee at their scheduled meeting on May 10th and 11th.

How Are You Feeling?

written [August 7, 2010](#)

I'm never sure how to answer this question. Most of the time I smile and give a joking response of some sort. But lately, as things have been harder, I've spent some time wondering how I would actually explain "How I feel" to someone (if they really wanted to know and weren't just being polite). I mean, is there a way to convey with words what it's like living in my body? I don't know - I've never tried. So I figured it's time for me to spend some time "trying" - though I don't know how long I will spend on it, or if I will even post it. Perhaps putting words to the pain will somehow make it easier to understand - limit it somehow so that it's easier to deal with. Maybe not... let's see how this goes...

CFIDS and Fibro cause quite a few different kinds of pain, and the Dysautonomia (a.k.a. POTS or Autonomic Nervous System Dysfunction) makes everything pretty complicated. A "good" day for me means that I just feel like I have flu. You know when you have a flu bug and your body aches and you're tired... that's my good day. That kind of day barely registers as painful for me - days like that are likely to be ones where I feel guilty if I'm not doing housework, educating the boys (though thankfully all their schoolwork is now pretty much done independently), whatever... those are the days when I feel like I should do as much as I can before an "average" (or, heaven forbid, a bad day) kicks in. (Of course, "day" here is used in a

very vague sense rather than in a strict “time” sense as any given day can begin “good” and change suddenly without warning.) I know most people who feel that way will stay in bed until they feel better – for me there is no such thing as “better” than that – if I’m going to get anything done, have any quality of life, then resting on those days is not a possibility. A “good” day is taken advantage of and lived to the fullest!

An “average, normal” day for me is a bit more painful. Aside from more severe “flu-like” aches everywhere (about how the normal person feels the day after REALLY over-doing it at the gym – that same burning/aching feeling that gets worse with movement) – there will be random sharp, stabbing pains knifing through my body – sometimes in the shoulder or forearm, sometimes in a hip, sometimes in the heart muscle or the diaphragm – no real rhyme or reason for it, it just happens. They tend to be fairly quick – and pretty shocking – I’ll usually stand really still for a minute or two to make sure it doesn’t come back after it’s gone. There will also be a “creeping/crawling” sensation on my skin in different areas of my body – sometimes like tiny stabbing needles, sometimes just like little bug legs or something icky like that – but it often makes me rub my legs, arms, face, back or anywhere else (trying to brush off anything that might be there). Hive-like itching is common on these days as well – without the rash. Sometimes I scratch until I bruise. Let’s see, these days I’ll have pain in my face along with a heaviness, but my eye won’t actually droop. Talking hurts my jaw muscles, but I do it anyway – at least until it builds so much I can’t stand it anymore. I’ll be able to walk fine, though the fatigue factor means I am winded easily. My blood pressure can be unpredictable – I’ll feel faint and shaky when it dips. My heart might ache a bit at times when the blood isn’t circulating through it properly. Sometimes I’ll develop a fairly minor random infection (skin, bladder, etc. – for these I use Grapefruit Seed Extract since I can’t tolerate antibiotics). My memory is unreliable on these days – while I’ll remember some things – I will be unable to predict just what I WON’T remember — usually something fairly obvious and important. (I’m a mom – it seems like EVERYTHING I forget is important to someone at some point!) I try to write lists – but most of the time I forget that the list exists... Sometimes it’s really crazy – I’ll remember the vaguest most “unlikely-to-be-remembered” things, and then forget if I’ve eaten breakfast or not. :)

Okay, moving onto a “bad” day (not really bad, mind you, just bad). Take everything from an “average” day and turn up the “dial” so to speak. Now I ache so bad it feels like my body is screaming when I sit up in the morning. (Usually sitting up will cause the knifing pains in my chest and back – makes the first few breaths a bit complicated – but it doesn’t last long.) You know in cartoons when a character hits his toe or something with a hammer and it “throbs” big and red? That’s how my whole body will feel. It literally feels like I’ve been smashed by something – I can feel my heart throb from my head to my toes. My bones themselves won’t ache though – only the muscles and joints. I might wake up feeling like someone has ripped me apart by the joints and shoved them back together. Not fun. Any itching will cause bruising when I scratch, which will hurt more than it should. It might hurt to touch areas of my skin that don’t even have any bruises (they’ll feel bruised, but there’s nothing there) – a drawback when you keep feeling like you have to brush off the crawling feeling! On a bad day, the pain in my face will intensify along with everything else, and my eye will droop – my face might hurt so bad that I just want to bury it in something soft – just to change the sensation. I probably won’t talk much on these days either because I’ll want to “save” my jaw muscle for things like eating or conversations that are absolutely necessary. The fatigue on these days makes even walking

through my tiny house an accomplishment. My day will usually be spent doing one thing like dishes, and then resting for a long time before the next thing as I catch my breath and build up energy. Any little movement will feel like exercising – or over exercising. My balance is off, so I might have to break down and use a cane to get around, just to make sure I don't fall (though I really try to avoid it because even my "light" cane is downright HEAVY on a bad day!) My blood pressure might dip so far unexpectedly that I can hit the ground in a faint before I know what's going on, but as soon as I'm horizontal I "wake up" – I'm never unconscious for long. Or it might be so low I can't really sit up without dizziness, nausea, and a horrible lead-like feeling in my chest. My heart might feel like it's being stabbed with a pencil through the lower left part – probably around the area that's developed a prolapse. Any existing infection will worsen of course. I'll also have vertigo and "sensory overload" that can cause nausea – ranging from queasiness to actual vomiting – usually hovering somewhere in the middle of that spectrum. My memory will be non-existent on a bad day. Just remembering to eat will be an accomplishment. Thank goodness for my boys! Growing boys aren't likely to let you forget a meal! :) Concentration will be almost impossible – it's hard to find words to say what I want to say, or something else entirely will come out of my mouth... Sometimes I'd like to cry, but I try not to because that makes my face hurt more...

A really bad day. These are the days when getting out of bed is not realistic – or just down right not possible. Thank the Lord, I haven't had a "really bad day" in awhile – not since I began seeing my new doc. I still have bad days, but prayerfully the "really bad" ones are in the past. I don't want to go into the reality of a really bad day – don't want to think about it that much... Suffice it to say, a really bad day takes the "bad day" and turns up the "dial" again...

So, that's how I feel... in all it's unpredictable glory. In reality any given day can move through the different levels from "good" to "bad" though. (Um, moving from "bad" to "good" doesn't happen – at least not for me.) Unfortunately, "overdoing" it when I have the energy to get things done usually means that I'll be moving towards "bad" sooner rather than later... but predicting what is or isn't "overdoing it" isn't always easy. (Though we discovered the other day that going "shopping" and walking around the store was just plain stupid. I was a mess for days afterwards – and I'm wondering if overdoing it too much during the past week caused my "episode" at the clinic on Wednesday – not that I'm going to go into detail about that right now.)

After reading this over, I don't really think that there's any real way to explain what this life is like... The physical issues are not really the worst part of it all – it's the emotional ones – the guilt, the lack of understanding from the rest of the world, all the expectations, the unfulfilled dreams, the "not living up to your potential," yada, yada, yada – it's the things other people think and say that hurt. The "why aren't you better yet" attitudes, and "what's wrong now" type comments. I don't just want to be well so that I can be free from the pain... I want the rest of the world off my back... Some days I'd just like to take my little family and "run away" where no one else can find us and the rest of the world can just go fly a kite. :) But I'm here... living this life moment by moment... and I've learned a lot about what it is to be human. Humans are fragile creatures... This is a humbling disease – as one of the ladies at the clinic said on Wednesday (we were talking about our hair loss)- and humility doesn't hurt once it's acquired...

Nowadays I'm pretty good at noticing when something doesn't hurt...

Please feel free to edit this as necessary - only I'd ask that you leave the last paragraph of the post in tact... because the worst part of this disease isn't the pain, the mental confusion, sensory overload, or anything physical - it's the attitude of others who don't "believe in it" - or don't think it's a big deal. Like I said in the blog post, I don't just want to be well to feel normal again - I want the rest of the world to get off my back. I want people to understand that I'm doing my very best... I'm trying to get better, I don't like being this way... I'd do anything to "get my old self" back. I want to be able to watch my boys grow up, I would love to be able to finish college and be part of the rest of the world... I'd love to go out with friends and not collapse afterwards... I'd love to be someone my family can be proud of, instead of someone to be avoided like I am with my siblings... It doesn't help that the name "CFS" sounds like it's no big deal...

I know that funding for research can be hard to come by, but I'd ask that there would at least be a concentrated effort to have this illness taken seriously... Would any of you like to live your life this way - and then be told repeatedly that it isn't a big deal... you're just a hypochondriac - a pathetic person looking for attention? We just want to be treated humanely... and helped if at all possible.

Sincerely,
Jennifer "Nonna" Buckley