Life As I Know It

What I want those who love me to know, and what I wish the rest of the world understood about living with chronic disease.

By Gina Samarotto

***Please don't tell me I need to keep a positive attitude*.**

I deal with my RA every day, and so I know just how emotionally and physically dangerous giving in to depression can be. Despair is awful and I wish (more than you know) that I could simply "snap out" of it when that feeling takes hold. I know you mean well when you to tell me not to let it get me down, but telling someone with a chronic disease that they "need to keep a positive attitude" is condescending – it makes me feel as if you're diminishing what I'm going through. Your well-intentioned pep talk doesn't help me rise above it at all, it leaves me feeling as if I've somehow failed.

The reality is, I live with a lot of pain and I exist in a state of nearly constant worry. No one knows why I have this debilitating disease or how I got it, but we do know that there is no cure for it.

On a day when I am able to function well, I worry about how many of those days I have left. I worry and wonder if this is the last day that I will be able to ____________ (fill in the blank) unassisted. On a day when I can't function well, my feelings are escalated into something that - to me, anyway - feels like the beginning of the end.

I struggle with this and more all day every day, so please - don't judge me when I give in to a setback or when I can't quite keep all those emotional plates spinning in the air. And please know that if I love and trust you enough to reach out to you when those plates fall and shatter, I don't need you to have all the answers - I just need you to be willing to listen.

I know that people who care about me have a hard time seeing me so depressed and down. It's difficult for ME to see myself that way, too. But telling me to 'buck up' doesn't help. It stings. A lot. And mostly because you don't realize the thousands of times I've done just that.

There are days when getting myself out of bed and dressed is an accomplishment that takes more than I think I have. There are days when my hands and wrists don't have the strength to lift a frying pan and so I shake it off and order pizza for dinner. There are days when I have to enable 'talk to type' on my computer because I'm under deadline and can't coax my stiff and swollen fingers into navigating a keyboard. There are times when it's taken me four days in bed to recover from two days on the road. And there are days when I've cried with pain and frustration in the shower, because it's the only place my family wouldn't hear me.

This is my new 'normal' and no, I'm not trying to make a martyr of myself. I am just trying to make you understand that pushing through clouds of pain and depression is not an unknown concept to me. I do it far more often than you might realize and I deserve credit for the times I succeed, not reprimand for the times I don't.

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Mean what you say, say what you mean and please, make it easy for me to accept your help.

When you live with a chronic disease, it's not easy to face the reality that you need help. It's even harder when that reality is met with vague, 'let me know if you need anything' statements – the kind that sound like something people say when they don't know what else to say.

Thankfully, I am blessed with people in my life who genuinely, sincerely want to help. Yet regardless of how heartfelt an offer may be, it's something that's never easy for me to hear.

Please know that I love and appreciate that you *want* to help. If I seem hesitant, it's because I really hate *accepting* help – even when you offer it. For me, the thought of being needy is embarrassing and the idea of being a burden terrifying. I am worried that I may unknowingly request something of you that you feel is too personal or inconvenient or frivolous. And sometimes I am so consumed by whatever challenges I'm facing that day, I can barely decipher what it is I need in the first place - let alone figure out a way to ask someone else to provide it. It's not that I don't need or appreciate your help, it's that I don't know how to ask for it gracefully.

What I can accept gracefully, though are offers that don't make me feel as if I'm asking the world of you. An, "I'm going to the drugstore, can I pick up your prescriptions while I'm there?" or "Are you feeling up to a visit this afternoon? I'm going to be in the neighborhood." or "I'm making lasagne today, can I drop some off to you?" or even "Holy roots, Batman! When am I coming over to slap some hair dye on that head of yours?" is priceless – and so much easier for me to accept.

No, you really DON'T know 'just how I feel' – and I don't expect you to.

I have no doubt that your knees creak and I'm sorry that your joints ache when it's raining. I know you honestly think you understand what I'm going through because you watch your grandmother/father/uncle/neighbor struggle with arthritis, too. (hint – what they probably have is osteoarthritis and yep, it's a bitch but it's not RA).

I know you are well-intentioned but unless you live with a painful, chronic disease – RA or otherwise - you have no clue what it's like. To put it in perspective, telling someone with RA that you know how they feel because you have arthritis in your knee is like telling Michael Phelps you know how he feels because you were on the high school swim team.

RA causes my body to attack its own tissue, meaning I live with pain that is at best omnipresent and at worse, horrific. And despite having the word 'arthritis' in its name, RA doesn't limit itself to joint damage. Given a chance RA may go after my lungs, heart, eyes, airways, blood vessels or organs. It's insidious, relentless and loves to keep me – and my doctors – guessing. What I have is a chronic, autoimmune disease that on a bad day leaves me feeling like I'm coming down with the flu after being hit by a train and on a REALLY bad day, lands me in bed with so much pain I can't move - but fortunately I'm way too sick to really care. And just in case that wasn't enough fun, RA (and ironically, the drugs used to control it) weakens your bones – bones already made vulnerable by a lack of cushioning normally provided by healthy joint tissue. As a result, my bones are more prone to fracture than they should be - as my recently broken ankle will attest. And as there is no cure RA, the best I can hope for is to slow the damage it causes – damage that once done, is permanent. I will have this disease it for the rest of my life and that life - according to statistics - may be shortened as a result of the disease.

So honestly, it's ok that you don't know how I feel – and I hope you never do.

It's really, really lonely.

Everyone has their own lives, I get that and I appreciate that. Really I do. But once the 'newness' of being sick or injured begins to wear off and visits from concerned friends and family start to taper off; prepare yourself for the very real likelihood of spending a fair amount of time feeling alone and abandoned.

That's hard every day and some days it's not just hard – it's brutal. Can't imagine what that must be like? Let me help you.

Imagine spending weeks in the house without ever going outside, seeing your friends or leaving your bed. Imagine being in pain and scared and heart-achingly sad over a holiday weekend where you have nothing to do but focus on how everyone you know had plans that didn't include you (some may say this is a moot point given you may not feel up to participating - but I assure you, not being asked makes a horrible situation worse). Imagine living vicariously through social media, but signing off when you just can't bear seeing all the festive posts from friends out celebrating while you're so depressed it physically hurts.

Imagine waking up in the morning and dreading the day in front of you because you know it means you'll be alone for hours on end. Imagine needing to talk to someone but not being able to because they're all busy – or worse, they're avoiding you because it's unpleasant and besides, they just 'don't know what to say'.

Imagine spending a day doing little more than imagining what it will be like to live in a wheelchair - because at that moment you can't imagine a day when your legs will ever be able to hold you up again. And then imagine trying to talk about how much the very idea of that terrifies you, but each time you try you just burst into tears.

THAT is the kind of loneliness and despair and depression I'm talking about.

If you find yourself in a similar position, know that I am going to be behind your door. Often. As in all the time until you can't stand the sight of me. Because I know all too well how awful it's going to feel if nobody does.

It could be worse.

Of course it could be worse, I could be dead.

In the grand scheme of disease, there are many far worse than RA. I know that. My mother never lived to see the age I am now so believe me, I get it. That said, knowing others have carried burdens heavier than mine doesn't leave me feeling particularly grateful to have RA.

I hide (lie) a lot.

I love to go out and explore a new place but I'll just tell you I just don't feel like it before I'll admit that my ankles and knees hurt too badly to walk anywhere. Before I had a handicap parking permit for my car (and before you celebrate the idea of unfiltered access to all the "best" parking spots, let me tell you how upsetting it is when a permanent disability earns you one of those placards), I might have cancelled lunch at the last minute by offering some lame (pardon the pun) excuse when the truth of the matter is that the walk to the door from the nearest parking spot was too much for me that day. I won't skate, bike, dance, hike or do anything even remotely aerobic without serious forethought… not because I don't want to, but because at this point I'm so afraid of breaking another bone it borders on phobic. I might tell you I have no time to garden but the real reason I don’t have flowers is because I am not able to kneel down or dig or prune or plant without pain.

You were doing so great yesterday.

Thanks for reminding me. And I might be doing great again next week. But right now – not so much.

Most days, there’s no way to predict how I’m going to feel. Some days it’s better and some days it’s worse. Some days I can power through it and some days I can’t. It’s baffling, it’s frustrating, and I don’t like it any more than you do.

You know, I bet you’d feel better if you stopped eating ___________.

Seriously!? I can’t believe all the time scientists have wasted trying to come up with a cure for this sucker when all you really have to do is give up carbs/red meat/high fructose corn syrup/red dye/gluten/vodka!? Do the cancer researchers know about this!? We should tell them right away!!

I assure you, if curing RA was that simple no one would have RA.

If you insist on telling me that eating (or not eating, as the case may be) a certain food is the reason I am going through this, I will beat you with the heaviest bag of sugar my joints allow me to lift.

Enough said.

Have You Tried ___________?

Yes. I know exercise is good for me. I also know that when I am experiencing a flare, just getting out of bed is a Herculean task. I do what I can, when I can.

I am also a big believer in alternative medicine. And yes, I understand that the supplements your sister-in-law’s brother’s godson took were nothing short of miraculous. I appreciate your wanting to help, I really do. But I am already taking enough drugs to down a wildebeest and I’m working with a barrage of well-trained specialists – all in an effort to manage my RA. So please don’t become offended if I don’t put your suggestion to immediate use. It’s just not that easy.

And do me (and everyone else with - and I quote, “moderate to severe RA for whom methotrexate did not work”) a favor and PLEASE don’t talk to me about the happy, prancing unicorn laden, rainbow spouting wonderland of life painted by drug manufacturers while telling the world about their magical, injectable biologics. These are scary, serious drugs. Like they’re used for chemotherapy kinda scary and you better hope you never get a serious infection while you’re on these because if you do you’ll probably die kinda serious.

No matter how alluring those commercials may look, there is no magic bullet. I really, really wish there was – but there isn’t.

For now, the best I can hope for is to be able to hang onto a little bit of my old life a little bit longer.