This Is What Rheumatoid Arthritis Actually Feels Like

by MARIAH LEACH

What Does Rheumatoid Arthritis Feel Like?

When I was first asked to write about what it feels like to live with rheumatoid arthritis (RA), I thought it would be pretty easy. After all, I've been living with RA for the last eight years — that should give me enough experience to explain what it's like.

But as I really started thinking about it, I realized it was more of a challenge than I expected. RA is something that impacts every day of my life — and yet it does not define me.

I spend a huge portion of my time thinking about my body and focusing on my health — and yet I often feel I can't trust my own body and I rarely consider myself healthy. How do you explain what that feels like to someone who hasn't personally experienced it?

One useful tool for explaining life with a chronic illness is Christine Miserandino's Spoon Theory. Though written as a metaphor for life with lupus, the spoon theory provides a tangible way to describe how chronic illness forces you to allocate very limited energy to complete ordinary tasks.

The spoon theory is also a good way of illustrating the enormous level of uncertainty that chronic illness can bring into your life.

But when it comes to RA specifically, the spoon theory falls short of explaining the impact of pain, both physically and emotionally. So, with my thought process temporarily stymied, I turned to my RA community on social media.

Sufferers Describe What RA Feels Like

I was curious to see how others living with RA would explain how it feels — particularly the impact of pain. The responses I received were both familiar and distinctive, so I wanted to share a few of them:

"I always describe RA as having the flu the day after a car accident." – Molly, age 36, living with arthritis for four years.

"I feel like a moody hormonal teenager most days. Some days I am able to move freely, no medicine, no one stopping me. Other days I can't open my hands, wear shoes, or even comfortably wear pants on my RA stricken hips.

My body feels like it's shutting down completely and no matter how much medication I take the only way I find relief is to remember in the back of my head that I'm going to be ok." – Karlie, age 25, living with arthritis for two years.

"I feel like most of the day I could lay down anywhere and take a nap, even after sleeping a full night. When joints

hurt the best way I can describe it is that it feels like a hammer hit me. It makes the joint so tender that even the thought of a bed sheet touching it makes you wince" – Brandi, age 33, living with arthritis for 20 years

"Some days it feels like I was brutally beaten up with a golf club, while other days it is more of a tight, throbbing ache — as if a vice grip is increasingly tightened around my joints or what I imagine it would feel like if a body could rust.

Imagine you've been forced into a box that is too small for your body, and you can't stretch or extend your joints. Each day can be a surprise as to which joints are affected; it is completely unpredictable. Will I be able to walk tomorrow or open my mouth to eat? Will I be able to lift my elbow to shampoo my hair or use my fingers to snap my infant's onesie?" – Jeanmarie, age 31, living with arthritis for six years

"It's a stabbing, sharp pain that stops you in your tracks. Or it's a dull but constant ache that stiffens your joints. It's telling your friends and family that you have to change plans at the last minute because your joints are suddenly swollen and inflamed. Or telling your kids you can't play today because you feel like you've been hit by a bus." – Christina, age 38, living with arthritis for 35 years

Pain Is a Part of Life

It's clear from these descriptions that the pain experienced by people living with RA varies quite a lot — how often you are in pain, which joints are affected, how much it hurts, what it feels like, and the way it impacts you emotionally. But one thing that all these descriptions have in common is that pain is an integral part of life with RA.

It cannot be ignored. And, realizing this, I was able to think up my own metaphor for life with RA.

RA Is the Pebble in Your Shoe

Living with RA feels like always having a pebble in your shoe. At first, you may not think that sounds like a very big deal — it's just a pebble, after all.

But soon you realize having a pebble in your shoe impacts almost everything you do. And sometimes the pebble is under a very tender part of your foot, so even ordinary tasks like walking or standing become excruciating.

Sometimes the pebble even cuts or bruises your foot, leaving you with an injury that hurts for weeks or months while the pebble continues its damage in another location.

Other times, the pebble moves into a roomier part of your shoe and you hardly notice it's there at all. Or, if you're lucky, you may be able to a pair of shoes that reduces the impact of the pebble.

In those cases, you may be able to do ordinary things without pain. But the uncertainty is always there. You never know which action may cause the pebble to move to another part of your shoe, making everyday life painful again.

And the pebble never ever goes away. For the rest of your life, you have to remember that there's a pebble in your shoe and make all of your plans accordingly.

Sometimes you really, really hate the pebble and you perseverate on the pain and unfairness of it all. But sometimes you meet someone else living with a pebble in their shoe, and you realize you can support each other in solidarity.

And, eventually, you hope to be able to find strength from living this way — and an intense appreciation for anything you are able to do without the pebble getting in the way.

The above article was originally written by Mariah Leech, who lives with rheumatoid arthritis and share her

perspective on what it is like to live with RA.

Next page: Another author who suffers from RA, Lana Barhum, talks about what rheumatoid arthritis feels like and how it affects her.

Lana's Perspective About What Rheumatoid Arthritis Feels Like

RA varies from person to person and no two people develop the disease in the same way.

For some people, RA develops gradually, and for others, there is a sudden onset with no explanation. Symptom severity varies by person, and disease progression can be mild, moderate or severe. And symptoms and progression change with time.

Some people with RA are lucky enough to experience remission, a period where disease activity stops. But for most, remission doesn't occur, and they have persistent symptoms that require aggressive treatments.

Making Sense of Symptoms

Doctors believe there are specific symptoms most people with RA experience and research shows for most people develop symptoms gradually.

Pain

In my early 20s, I started experiencing on-and-off joint pain and extreme fatigue that would stick around for a short period and dissipate. This made it difficult for my doctor to diagnose me with RA and any other condition.

Early on, most people with RA experience joint pain and stiffness and in some, there is also a limited range of motion in those affected joints. But most people suspect an injury rather than a chronic, life-changing disease.

With injuries, the body eventually heals, and life goes back to normal. Imagine having to deal with pain, stiffness, and range of motion problems almost daily as is the case with RA.

Comparing Flares to the Flu

RA brings painful flare-ups. These are periods where the disease flares-up and causes pain and a whole host of symptoms.

RA can be described similarly to having a bad flu where your body is aching from head to toe, and your muscles are weak. You might experience a fever, nausea and vomiting and a loss of appetite.

That awful sickness, exhaustion, and inability to get out of bed are what RA flares can feel like. The difference, however, is that the flu gets better with time and you eventually go on with your life.

With RA, recovery isn't possible, and the fever, exhaustion, and aches always return.

Physical Exhaustion

Perhaps you just finished moving, planning and/or decorating for a holiday party. After these types of tasks, your body feels tired, your muscles are weak, you're out of breath, and your body and mind cannot take on any more.

After a good night's sleep, you will be refreshed and ready to handle the next day's challenges, but you can't do that with RA as a good night's sleep rarely does much to get your energy back.

You Never Know What is Next

Imagine feeling okay when you wake up in the morning but by evening you feel like you were hit by a cement truck. These symptoms come without warning and not knowing when they will happen can be scary.

Sometimes, no matter how hard you try, you cannot avoid the pain of RA. Symptoms of RA and flare-ups have a mind of their own, and often, there is little control you have over preventing them.

RA Is a Constant Companion

The thing to understand about RA is that it is always there and it is a constant companion for most of us. Some days might better than others, but most of us have pain and symptoms every single day.

I have pain every day. Some days, it is mild, and I can do a lot – not as much as someone without RA, but a lot more than usual. Even on the days where it the pain and fatigue are bad, I try to put on my best face and deal with it because I don't have a choice.

There are times where it seems I am flaring all the time and some flares seem to last days or even weeks. And in all these nine years of living with this disease, I have had a handful of flares that have gone on for months.

RA Affects Every Part of You and Your Life

There are days where my RA feels like I have sprained and injured every single joint in my body – my ankles, wrists, knees, fingers, toes, ribs, shoulders and hips. There is not enough anti-inflammatory medication or a big enough heating pad to give me relief.

Then there is fatigue – unrelenting fatigue – all the time. I need more coffee to wake me up, and no matter how much sleep I get, I can't seem to get enough. I can't sleep my life away, and I wish I didn't need as much rest as I do. But I keep moving forward like a functioning zombie who manages to hide amongst the human race.

My rheumatologist isn't a fan of prescribing strong pain medications, but she knows me well enough to know that I am struggling. I put up with a lot when it comes to my RA symptoms and pain and most people in my life have no idea of my ordeal.

I'd wish I could say I am proud of the fact that I hide having RA so well, but I am not proud of it. In fact, I wish I could speak up but speaking up changes everything.

Speaking up – at least from my perspective – would mean that I would be viewed as incapable at my job, as a mother, and as a human being. So, I don't and neither do others with RA because society has associated a stigma with RA, chronic illness, and pain.

Not Just Physical

RA doesn't just affect you physically. It brings with it emotional struggles. After all, living with a disease that is unpredictable, tiring and physically draining takes everything you have to stay emotionally sane.

RA can be devastating, and it makes the simplest tasks – like tying your shoes or opening a jar – daunting. Activities you once enjoyed, such as working with tools or running marathons, become challenging to do and less enjoyable because of pain.

Perhaps even your career has suffered, as this was the case for me. I was looking at law schools when I was diagnosed with RA and being sick, going to law school, working and caring for my family was too much to handle and I had to give something up.

All the limitations RA brings are overwhelming and stressful. Even if you can cope with all the change, RA symptoms themselves also cause depression and anxiety.

People with RA are twice as likely to become depressed, this according to the Arthritis Foundation. Moreover, living with physical pain causes anxiety which may eventually become a full anxiety disorder.

These days, I try a little harder not to let the things RA has taken from me get to me. I try to move forward, but there are plenty of times where I feel suck and feeling stuck is depressing.

Like so many with RA, I wasn’t spared from depression. In fact, depression has taken its hold on me many times in the last nine years.

From Lana's Perspective

I have explained what RA is like from my perspective but I am only one person - one RA sufferer - and I can’t speak concisely or correctly for others with RA. I can just offer a general message and speak from my own experiences.

I know having an unpredictable illness is something that can be indescribable and sometimes, and try to share my journey is difficult to put into words. But I hope my struggle gives insight into what it can be like and how difficult is to live with RA.