

On being a chronically ill photographer

Throughout the time of being chronically ill I learned to love photography and developed a whole new view of all things surrounding me, I'd even say I developed a new relationship with my surroundings, especially with nature.

I never despised nature, but it was only when I became chronically ill and leaving the house wasn't easy and natural anymore, that I understood the importance of nature for me.

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Healthy people imagine being in bed the whole day as some relaxing and even comforting experience. You can watch tv, stay in your pyjamas the whole day and eat whatever...hooray! Well, not exactly true for me. If you can't leave the house, your house becomes a prison. Every moment outside gains so much value and has to be treasured!

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My camera doesn't cure me of my illness of course. But my camera allows me to capture moments, landscapes, flowers, animals, everything that makes the world outside such a beautiful magical experience. Everytime I go out, I take as many pictures as I can so on my bad days, when even sitting gets troublesome, I flip through my old pictures and feel comforted. Comforted, that I got to experience all those beautiful moments and that I can re-live them visually and in my imagination.

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However, even on my „good days“, when I can leave the house, it happens, that I feel too weak and dizzy to carry the weight of my camera. Yes, this is part of the reality of living with chronic illness as well - having to consider if the weight of the camera in your backpack is the weight that is just too much for you to carry; realizing that your joints just hurt too much today for lifting it or that you are too dizzy to stand still long enough to take a sharp picture (yeah, tripods do help but also add extra weight!).

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No need to feel sorry for me - I love my life!

But I gladly take empathy or real interest in how living with ME is - as well as solidarity. You can direct the sympathy to the fact that there still is this lack of funding for ME research, even though millions of people worldwide struggle. Millions. And now with Covid it will be even more.

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Solidarity by the way starts with just believing people what they say, even if you have not experienced it yourself. Disbelieve just hurts and adds more unnecessary struggle on top of it all. Chronic illness is not static, abilities and limitations can change even within a day! I know, this seems hard to grasp at first, but please try to wrap your mind around and don't make any sick person feel bad for experiencing a good day with more energy and less discomfort. Don't accuse them of faking, it is hard enough to go through life with chronic illness.

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What about showing real interest instead of assuming things and then getting mad or envious when your assumptions are not met? =)