

# What I Wish...



**MS symptoms vary from person to person. Even more, symptoms are often invisible. Because of this, it can be difficult to describe your symptoms or get someone to relate to your experience.**

For MS Awareness Week (March 11-17), we asked you, “what do you wish people knew about MS?” Here’s what you said.

## **1) MS can feel like a burden.**

**Mileana Johnson-Coryea** That I really do want to do more. I want to have my body, energy, brain back. I hate feeling like I'm a disappointment/embarrassment to my husband and kids.

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**Christy Bernardin** The guilt I feel when I can't do something!

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## **2) It's often on the back of your mind.**

**Dina** That it never goes away. Ever. It's always there. You could be having the best day but somehow something always reminds you that you have MS and there is no cure.

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## **3) The over-looked cognitive challenges with MS.**

**Laura West** That the emotional and cognitive changes and symptoms are harder for me to accept than the physical, and my frustration in having to repeat myself or in asking you to repeat something again and again are with myself and my disease, not you. I'm learning everyday how to adapt to the cognitive and emotional changes in the same way I've learned to adapt to the physical challenges, on the days it's apparent I'm struggling, please just give me a little extra grace and patience. I'm trying to adapt to losing who I feel I am.

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#### 4) The fear of disease progression.

**Monica Sellers** Fatigue. Vertigo. Looks are deceiving, it's exhausting, it never goes away and the fear of things getting worse is real. Will I be able to walk tomorrow? Will I be able to see tomorrow? Will my vision come back? Everyone's MS is different and that's frustrating too. It's scary. You can't get too hot or too cold, it depletes all your energy.

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**Lindsey Pichette** I wish people knew that even though I smile I'm scared of the unknown of MS.

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#### 5) The effort it can take to just get through the day.

**Kristin** Honestly I wish there was a way people could actually experience my day and understand when I show up for stuff I put all my energy into being there so that I can feel like a normal human being for a little bit.

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#### 6) The disease is unpredictable.

**Meggen** Some days I feel like I could climb a mountain, and other days getting out of bed is a task. Some days I'm sharp as a tack, and others I can feel my brain function diminishing before my eyes. Not being able to fully rely on body and/or mind is taxing in and of itself.

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#### 7) Because MS affects your nervous system, symptoms can be wide and varied.

**Jarred Peters** That though we may look like we're doing fine to others we are often carrying a heavy burden of suffering from a multitude of symptoms all of which are difficult to truly understand unless you live a day in our bodies #ThisIsMS

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## 8) Taking care of yourself mentally is a big part of living with this disease.

**Gary R. Held** That your attitude about MS makes a HUGE difference. I have lived with MS for 40 years and treat it as an inconvenience. I have watched it progress from R&R to Secondary Progressive and I have experienced the disappointment of giving up things that I love, but I still love life and am blessed that I get up every day and enjoy it.

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## 9) Just because you can't see the symptoms doesn't mean they're not there.

**Rene Wilkins** That just because you can't see it doesn't mean there is nothing wrong. The pain and struggle is real.

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## 10) MS can affect the people around you.

**Carolyn Ingold** That it is just as hard on your loved ones as it is on you. 😞😞

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## 11) People living with MS are resilient.

**Lindsay Fryer** That I don't need/want pity. I hate that look people give you when they find out you have MS. I don't want wrapping in cotton wool! And I intend to use every second of my fully mobile life while I still have it!! And if I DO end up in a wheelchair, then I'll be trying to figure out a way to get to the ParaOlympics to continue that life!! Happy Friday! 😊

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## 12) Life does not end because of MS.

**Trudee Manderfield** I wish people knew it's possible to live a fulfilling life with MS. It's a lot to overcome, but it's not a death sentence. There is life after diagnosis.

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We want to know: what do you wish people knew about MS? Do you agree with any of the thoughts above?