

Accelerated Cure Project for MS

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Unwell Adventures – “The Power of Social Media for Good”

An MS diagnosis brings with it a wide range of powerful emotions. Some may feel angry, teary or afraid. Others may feel relieved, especially if they’ve spent months, or even years, trying to understand the reason for their symptoms. If MS manifests itself suddenly and a diagnosis is made quickly, one may feel shocked. Others may feel like it’s unreal, happening to someone else, or even a lack of emotion.



Samantha Leathers was diagnosed with MS in 2017, at the age of 27, 3 months after she got married. She had just lost one of her best friends to terminal brain cancer. Samantha started having numbness and tingling in her hand and thought it was carpal tunnel syndrome. The day her friend passed away, her whole left side went numb. Samantha thought she was having a physical reaction to grief. She went to a walk-in clinic the day after the funeral and was blindsided when the doctor said, “I think you have MS.” He sent her away without offering any more information, suggesting she see her primary care physician.

At the suggestion of an MS diagnosis, the first person Samantha called was her mother, Sarah. They immediately took action and changed Samantha’s diet completely, removing the most inflammatory foods (gluten, dairy, soy and corn). Samantha went to an MS specialist at Columbia Medical Center and was officially diagnosed within three months. She started Copaxone right away, but her disease continued to flare which made for a difficult first year. Fortunately, since switching to Rituximab, she has been relapse-free for the past year. In Samantha’s words, “I don’t feel like a sick person. It’s been life changing. I don’t know what the future holds, for right now I’m very grateful.”

Samantha has a great passion for travel and new adventures. In her words, “Travel has been a big part of my life. It’s a part of my identity and who I am. It’s more than just travel, it’s about experiencing new things and trying new activities. That’s what keeps my blood flowing.” One of the most meaningful places she visited was Ghana, West Africa. Samantha took a break from college to volunteer at an orphanage there on and off for two years. When asked to describe this experience and the influence it had on her life, Samantha said, “The situation there was very remote and it was pretty dire. It was a crazy experience that’s really created and reinforced who I am. It’s put me on a path to where I am.” Samantha and her husband look forward to their next big adventure in the spring, a trip to Tel Aviv and Petra.



Seven months ago, Samantha decided she wanted to share her MS journey with others who may be struggling in the same circumstance. She started her [Instagram account](#), called [Unwell Adventures](#). She began by posting stories describing her first year when she was experiencing MS flares, as well as things that were helpful during that difficult time. Samantha shares, “I didn’t start it when I was diagnosed, I waited a year because I was scared. I went through a time when I didn’t tell a lot of people. My emotions were at the brim. I was in survival mode. Once I started to be more open I realized how great that was... When you’re told you have MS, your first thought is that you’re going to be in a wheelchair. People who are newly diagnosed don’t hear about the people who are doing well and it feels like this terminal diagnosis. There are so many people who



manage and all of those stories get lost... My husband and I went to Thailand and Cambodia last year. People looked at the pictures and said, ‘You don’t look sick.’ They didn’t see the fact that I was having my biggest flare up while I was there. I could barely walk. I used Instagram to shed light on the fact that I was there, it was beautiful, but I was crawling up the side of a temple. It’s one of those moments that I had to laugh because it was ridiculous, but I don’t want to miss out on life. That was a very powerful moment.” Samantha uses Unwell Adventures to share snippets, or [stories](#), from her daily life. She explains, “I typically share the days I have infusions because that’s a really vulnerable time for me. I try and make it light hearted,

because that’s just who I am. I try to be as authentic as possible.” Samantha also shares deeper moments on her [Instagram feed](#). In her words, “These are the things I really want to have a deeper discussion about. For example, talking about how I’m feeling, or I went mountain biking for the first time. Putting a caption to it that I tried this new activity and it made me feel alive. I want that to really live there as that message.”

Today, Unwell Adventures has almost 400 followers, both with and without MS. Samantha not only offers support to others, but has also found it to be a great source of encouragement herself. She shares, “No matter how amazing your support system is, they won’t ever be able to really understand. My husband is amazing, my parents and the rest of my family are amazing. They support me. I could not be more grateful. At the end of the day, they don’t know what it feels like. I’ve found support and connection through Unwell Adventures. This is the power of social media for good.” When Samantha went to her first MS event, it was an

overwhelming experience. In her words, “I had an absolute breakdown, which I didn’t expect. I contacted one of my MS buddies and she understood. That’s an amazing gift I wouldn’t have had if it weren’t for Unwell Adventures... The engagement has been really incredible. I’ve also been able to connect with people who have other autoimmune diseases. Because the feelings of fear, the lack of control, all of those emotions go with anything. Being able to talk about taking back some control, whether it be diet or fitness, has really translated with a lot of other people as well as the MS community.”



Samantha’s mission for Unwell Adventures is multifaceted. She explains, “I want to give a voice to a generation of MSers in their late 20’s, of which there is a very large population, and provide more relatable resources for families, for people going through it.” Samantha hopes that Unwell Adventures will also help to invoke people’s resilience. In her words, “Resilient is now a word that I love deeply. I’m not necessarily working toward a cure because right now there isn’t one. I’m working to live my life with this disease forever. There’s this sense of resiliency and strength in so many people I’ve met with MS, it’s been so humbling. I just hope to continue to propel that.”

Anyone interested in following [Unwell Adventures](#) must download the Instagram App from the [App store](#) or [Google Play](#). Unwell Adventures can be found by searching for it by name within the App, or other MS-related hash tags, such as #ms, #strongerthanms, or #themssociety. For those curious how it got its name, Samantha shares, “Some think ‘unwell’ has a negative connotation. I think it’s kind of sarcastic, it’s sassy which is kind of ‘me’. It’s perfect. It’s like that moment in Cambodia when I thought my life was exploding, but it was also kind of an adventure and I still wanted to live it. I played around with all of these positive names and they were beautiful, but they just didn’t really seem to fit. I wanted to show the imperfect struggle and share that vulnerability of life.”

When asked what she enjoys most about Unwell Adventures, Samantha states, “The support and reinforcement that I’ve gotten. Being able to connect with people who I feel like I can really make a difference with, and vice versa. It really feels like I’m doing what I’m supposed to be doing.” When asked what her biggest challenge has been, she shares, “Being as vulnerable as I feel like I should be.” When asked if she has a message she would like to share with others recently diagnosed with MS, Samantha replies, “I would say just try to stay positive. It is so overwhelming at first because you’re scared, you’re trying to take care of yourself, and you don’t know what’s going on. Looking back, it was such an emotional time... Remember you are not alone, share with people. Don’t keep it in. Obviously you don’t have to tell everybody, but lean on your resources because they also want to be there for you... You’re going to get through it. You’re going to figure it out.”



Samantha is a Brand Marketing manager for an organic granola company. She is also a student at the [Institute for Integrative Nutrition](#), working toward getting her health-coaching certificate. In the future, she would like to start doing health and lifestyle coaching through Unwell Adventures, sharing the importance of fitness,

exercise and maintaining a routine with others living with MS. If you haven't already done so, consider following Unwell Adventures today. Whether you have MS or not, Samantha's positive, can-do attitude is infectious and is sure to add a ray of sunshine to your day.

