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Walk a Mile in My Shoes

Announcer:

Welcome to CME on ReachMD. This episode is part of our MinuteCE curriculum.

Prior to beginning the activity, please be sure to review the faculty and commercial support disclosure statements as well as the learning objectives.

Dr. Kowdley:

This is CME on ReachMD, and I'm Dr. Kris Kowdley. Here with me today is a patient with PBC, Maria. Maria represents an important group of patients that we must not ignore. She had a fairly rapid progression of disease from a diagnosis in 2017, and actually leading to liver transplant in 2021. So, Maria, please share your experience with us and thank you again for being so generous to share your story and your journey.

Maria:

Thank you, Dr. Kowdley. It's a pleasure to be here and talk about my lived experience. I also wanted to mention, not even just being a patient living with PBC, I'm also a registered nurse, so that puts into a perspective of, you know, the knowledge that I bring and the outcomes that I experienced.

So the PBC certainly affected my overall quality of life. Managing symptoms associated with PBC has been life-changing for sure. And as my disease progressed, it became even more difficult to cope with, both from a physical and psychological perspective.

So my disease symptoms included extreme fatigue, relentless itching, severe ascites, hepatic encephalopathy. I fell several times. My cognitive memory, thinking, was not the same as what I used to be. My hair fell out in clumps. I lost about 50 pounds of weight and muscle mass.

So as I became sicker and more debilitated with the fatigue, the itch, and large amount of weekly ascites drains for, you know, an incredible 10 liters of fluid that were drained, it really, really impacted my ability to deal with daily living, and it affected me every single day and moment. The itch became uncontrollable and inconsolable. It was a constant preoccupation, how to get rid of this itch and this nuisance. I would scratch various areas of my body, and that seemed to trigger other areas of itchiness, and I just couldn't stop myself. Being in social situations was embarrassing and awkward as people would wonder what was wrong and why I felt the need to obsessively and insistently scratch my skin, and it became really awkward. People would look at me with concern, and with this concern of wondering whether it was contagious or not.

My sleep also started to be unpredictable. I had a hard time getting restful sleep at night. It would often be 2, 3 o'clock in the morning and I still wouldn't be able to fall asleep. And of course, I would sleep in until about 1 o'clock in the afternoon and still not feel rested or refreshed, and I just literally could not get off the couch to do simple chores. And I often had this mental debate going on with myself to tell my body to get up, but my body would not listen to my mind. It was just a loss of control, a huge change in the kind of person I used to be years prior. You know, someone who was very productive, a wife, a mother, a friend, a nurse, a people-leader, and it was just disheartening.

Dr. Kowdley:

Yeah. Thank you, Maria, for sharing your journey and your experience.

So I would say the key takeaway from this experience and this anecdote that you've shared with us, is that we need to focus on symptoms as well as disease stage, and we need to meet patients where they are and really recognize the fact that the symptoms can be so disabling that they can lead to social isolation and depression, anxiety, etc.

So thank you very much for sharing your perspective with us. I hope it has been informative for our listeners.

Announcer:

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