My MF Story

As shared by James P.

I'm James. I have never written about my condition before and hope my story is one that, whomever reads it, finds something helpful.

I am from the UK and was 45 years old when I was diagnosed with mycosis fungoides (MF), stage 1A back in 2018. The path to diagnosis was unusual (having read others' stories) in that, while I had lived with these strange-looking patches on my torso for around 12 months, I put them down to eczema or psoriasis brought on by stress. It was only after trying a range of over-the-counter medicines—and seeing no change—that I went to the doctors to seek more information about the condition and treatment options. The first doctor I saw, what we call a General Practitioner (GP), was friendly but also thought it was just common old eczema. But after I went through the treatments I'd tried and the lack of results, the GP agreed it was worth me seeing a dermatologist.

"Well, this is interesting"

A few weeks passed until my appointment came up, and I walked into the office of my dermatologist. After an explanatory chat, they asked to see the patches. What I then recall was what felt like a much longer inspection than I was expecting…and the words I can still recall: "Well, this is interesting." I am sure most people don't really want to hear those words from their doctor! They explained that, while it was very unlikely—given how rare it is—to be a condition called mycosis fungoides, they still wanted to send me for a biopsy. The word "biopsy" was the point that I thought…Oh, this might be serious.

The next phase was a couple of biopsies (the first was inconclusive), but by the second, my dermatologist sat me down and said that, based on the results, it was cutaneous T-cell lymphoma. Now, at the word "lymphoma," I had a reaction that was stronger than at the word "biopsy." I knew lymphoma meant cancer, and as such, my mind raced. My doctor was very good—they explained the nature of blood cancers that manifest on the skin and the treatment options. I always remember coming away with the phrase in my head: "For the vast majority of people, this is a cancer you should die with rather than from." That was, and is, a source of much reassurance.

Next Phase…Treatment

The next phase was treatment, and I will briefly share what I undertook and the relative effects of each. For treatment options, I was referred to a cutaneous lymphoma specialist at Guy's and St Thomas'—who many in this community know—and was further comforted by what was clear: that in a world of rare cancers, I had the most common variant of a rare cancer. His calm, friendly demeanour, which gave off an air of "you are one of the easier ones I have to deal with," did reassure me. He outlined the range of options, and we agreed to start with UVB therapy.

After trudging to a clinic every few days to build up the dose, by the end of the course it made very little difference, so we moved to PUVA. Getting access to the psoralen was lengthy and expensive, and the treatment—where I had to visit a clinic a long way from home for a session that often lasted just a few minutes—was a pain, especially as it involved travelling during the pandemic, which was challenging. By the end of the treatment however, it had some effect—not complete remission, but an improvement.

He next suggested chlormethine (Ledaga in the UK), and after taking on board that it's a form of mustard gas (!)

and highly toxic, I knew that I wanted something that I could use at home to treat the condition. I am very glad I did, as I have found it excellent—by far the best treatment for me. Over a period of weeks, it darkened and then cleared my plaques, and I use it to this day when a new plaque pops up.

Seven Years On

So, I have now lived with this condition for 7 years. What are my main thoughts? I feel a bit of a fraud when it is described as a cancer, as it feels so much more manageable than many cancers. It has not prevented me from doing anything in life that I would have done anyway, and I feel very lucky to have had an early diagnosis and been under the care of great people with smart treatment options. I know not everyone's path to diagnosis and treatment has been as smooth, from listening to stories at the wonderful Patient Conference I attended in Philadelphia last year. Again, I am grateful that the community exists and to share stories of our respective journeys.

Seven years on, it is part of the fabric of my life, and I don't really give it much day-to-day thought…and frankly, long may that continue. I hope my doctor's initial words upon diagnosis remain true…I'll die with it rather than from it.