My new normal: A patient's perspective on polymyalgia rheumatica

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1 | LITTLE WHITE PILL

I wake from uncomfortable sleep at around 03:30—my new normal. The heat has not come on yet and this December’s Full Cold Moon already promises another dreary dank mid-Atlantic winter day. After my “Rise to the pain?” internal debate, I succumb—horizontal isn’t much better than vertical at this time of day. I leverage myself out of bed, wince, robe, and edge downstairs on unsteady feet. My morning leg and knee pain symptoms have flared again, 25 mg of prednisone per day notwithstanding. With a pain level 3-4 out of 10, it is certainly bearable, but it’s all wrong. I curse. Clearly my lowest effective dose has not yet been achieved, something I’ve known for over a week but which has not been appreciated by my rheumatologist. I medicate, eat breakfast, feed the cat, wake the iMac, hit play on Music… to hear Billy Joel sing about his friend John in the piano bar and that “someplace that he’d rather be.”

Yes indeed, I can think of a number of someplaces I’d rather be, healthy someplaces at that. Instead, my present choices are of either taking prednisone daily for the foreseeable future or pulling a cart of pain up a muddy winding road in the pouring rain, slogging through, yoked to this poorly understood polymyalgia rheumatica (PMR) for however-many months or years. This is my new normal.

Polymyalgia rheumatica is a chronic, extremely painful, autoimmune disorder primarily involving severe muscle pain the shoulders, hips and major joints. It affects about 0.1% of the over-50 population. More frequent in women than men, it targets most often those above age 60, with an average age at diagnosis of 70. I’m not at risk of death from it—as long as I don’t also develop giant cell arteritis, PMR’s dangerous cousin. But I sure have been suffering greatly. I am middle-aged and was otherwise healthy. At the time of this writing, my own treacherous PMR journey had only lasted for about 3 months and it had been 1 month since the official diagnosis. Most patients suffer for at least 1-2 years, and some for 5 or 8 years or more, during what should be their joyful golden years. And with no known cure, the primary treatment is symptom management with the Devil’s Tic Tacs: prednisone, doled out in generous milligrams, with goals of future tapering to a lower, more manageable dose.

2 | ELUSIVE DIAGNOSIS

Patients approach PMR with confusion and uncertainty and dread. It is so elusive to us in part because it is so elusive to our physicians and caregivers. Fellow patients describe stories of suffering with debilitating pain—joint-freezing, freedom-crippling pain—for months or years without a proper diagnosis or treatment. While many patients I know receive sound medical care, stories come up frequently of ignorant general practitioners and rheumatologists, well-meaning but undereducated clinicians simply throwing corticosteroids and NSAIDs and opioid pain killers at the symptoms, but offering neither sufficient information nor warning about possible drug interactions. Even if we are successfully treated to mitigate symptoms, our prognosis is vague. The reality is that our unbearable past and our tolerable present have become our future.

The later age-of-onset for most patients means that a PMR diagnosis might be masked by or confused with other complex geriatric-onset conditions: osteoarthritis, degenerative skeletal conditions, or complications from type 2 diabetes. Ironically, it also makes PMR more difficult to recognize in younger, generally healthy patients such as myself, with symptoms presenting in their 40s or 50s. Triggers for PMR pain flare-ups are poorly understood and range from physical overexertion to emotional stress and secondary medical conditions. The most effective symptom relief comes from

Dr. Paalman contributed to this article in his personal capacity and not as part of his official duties for Wiley Periodicals, Inc.

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prednisone, with a goal of reducing over time the daily dose as much as possible. When you have gradually and successfully tapered down from 20 mg/d prednisone to 8 mg/d over several months, only to be ordered to drop immediately to 5 mg/d due to an urgently needed Mohs surgery for skin cancer, the ramifications for a relapse with no effective short-term pain treatment can be profound.

3 | PERSONAL JOURNEY

I am a married, middle-aged professional with many annual travel obligations plus three children spanning middle school to university. I’m also a few years younger and possibly a little more active than some PMR sufferers. While I cannot speak for all patients, my journey through pain, diagnosis and management follows a common theme.

Prior to my diagnosis, I had been suffering low-level symptoms for about 2 months as moderate bilateral shoulder soreness that was not due to any known injury or accident. I also was experiencing increased hip-girdle discomfort. However, my lower-extremity pain was masked by a years-old lumbar spine and sacroiliac joint problem that caused intermittent lower back pain and sciatica. My back issues had been diagnosed through MRI imaging 5 years prior and were managed well through chiropractic treatment, physical therapy, and core-strength exercise.

It was during an October 2019 business trip that my then-unbeknownst-to-me PMR symptoms fully developed, a heavy load which I could barely drag from meeting to meeting. It was untreatable by mere over-the-counter means, which I discovered after much naproxen and over a hundred dollars’ worth of useless pain relief creams and patches. That business trip was truly a miserable one—but I couldn’t let it show, not in professional company. Skulking back to my room late each evening for solitude brought vague relief followed by yet another painful sleepless night, for reasons I could not fathom. Those bedtime shots of Maker’s Mark were a waste of perfectly good barleycorn mash—making mind dull and body worse.

Upon my return, my family could not understand at all what I was going through but certainly appreciated that it wasn’t good. I was first diagnosed by a sports medicine physician as having a rotator cuff injury and received a cortisone shot, which worked fabulously well for 2–3 days, relieving all of my pain, even the hips and legs… until it wore off. Then, during the next 2 weeks, I consumed two methylprednisone dose packs, each of which worked fabulously well for the first 2 days, until the daily taper went down below 20 mg. Next came a rheumatologist and my first official PMR diagnosis, based on blood work (which was off the charts) and an MRI showing only minor shoulder damage as would be expected for a 56-year-old, active male with a history of martial arts training and instruction. I was prescribed a cautious prednisone dose at first, 15 mg/d, which was increased to 20 mg after 2 days to make the symptoms more manageable. Five more days of discomfort later, my pain and joint mobility were still interfering with quality of life.

This treatment was clearly not working. Over a weekend and with no doctor consult available, I took it upon myself to increase my dose to 35 mg/d for 2 days and thus probed on my own the lowest effective dose for pain management. This both (a) worked fabulously well; and (b) horrified my young rheumatologist. “I was serious about the side effects of steroids, especially on the immune system,” said my doctor upon my confession. “At these doses, steroids are as strong as chemotherapy for shutting down immune function!” Whether that was true or not, it gave me pause. But my “curse” is that I’m a scientist-patient, willing to research the literature, listen to other patient experiences, and experiment with unharmful supplements (e.g., turmeric, palmitoylethanolamide, or omega-3 fatty acids) and even low-carbohydrate, inflammation-trigger eliminating diets in order to find my optimal personal treatment. In fact, I have found that most PMR patients, after an initial learning curve, are profoundly well-informed, often more so than their caregivers. Indeed, they need to be.
4 | POSSIBLE SIDE EFFECTS INCLUDE DEATH

Granted, patient experimentation is not advised with any medication. Pharmaceuticals like prednisone have a number of possible side effects and some can be serious. Some PMR patients taking prednisone report considerable mood swings, edema, weight gain, infection susceptibility, bone degeneration—the list goes on. However, many PMR patients such as myself... do not. Therefore, appreciation of the term “possible side effects” for a certain drug is also due, in the context of the individual patient.

One gets numbed to side-effect warnings on those TV advertisements from big pharma companies. They caution us to not take a given medication if we are allergic to that medication, or that a post -

Pharmaceuticals like prednisone have a number of possible side effects. Granted, patient experimentation is not advised with any medication. Therefore, at the time of drafting this manuscript, I was seeking a second opinion. By the time of final proof-editing, I had found a new rheumatologist who practices the “n = 1” philosophy.

My polling of PMR patients in a large international PMR support group on Facebook (https://www.facebook.com/groups/PMRpolymyalgia/) revealed three typical relationship scenarios with their healthcare providers:

1. Ignorant general practitioners who offer a mis-diagnosis or who can diagnose PMR but provide ineffective or even contraindicated treatment;
2. GPs or rheumatologists who appear to correctly diagnose PMR but who are profoundly risk-averse, and/or who treat patients as if they are children who must be told what’s good for them, and by extension, what their pain tolerance should be;
3. Educated physicians who develop relationships with their patients in which both parties are forthcoming and will consider medical prudence and patient circumstances in both diagnosis and treatment.

Scenario 1 demands a second opinion; hopefully, the patient becomes self-informed at best, or at least simply has enough of inadequate care and seeks help elsewhere. Likewise, if a relationship stuck in Scenario 2 cannot be moved to that of Scenario 3, then shopping for a better rheumatologist seems appropriate. It is my sincere hope that through education and collaboration, Scenario 3 will reign for PMR patients and their caregivers.

What treatment options present which likely risks? How does the provider mitigate risk while maximizing long-term symptom relief for their patient? Are providers willing to admit that they might not know enough about this poorly understood disease, but then actually study up? Do they understand that their patients are also quite capable of learning and participating in their own healthcare decisions through knowledge gleaned from educational services and patient support groups? The answers to these questions are at the forefront of the minds of my heroic PMR friends.

5 | PATIENT-PHYSICIAN SCENARIOS

In summary: I was a suffering patient who felt that he was not being listened to by his doctor. This leads me to the “n = 1” concept of patient treatment, which was related to me by a medical colleague. As part of a physician’s oath to “do no harm,” it is incumbent on the patient to follow that physician’s orders. That said, regardless of, for example, the possible side effect range of a given drug, every physician must perform a unique cost-benefit analysis for every patient. I’ve witnessed this through other PMR patients who have rheumatologists who come across as informed professionals willing to listen, reconsider, and above all, mutually educate. This positive-feedback dynamic is something that, try as I might, I had not achieved with my first rheumatologist. Therefore, at the time of drafting this manuscript, I was seeking a second opinion.

Since I’ve been diagnosed with PMR, it has made me both less and more miserable. Less miserable, since I know what ails me and I know that the symptoms are treatable. But also more miserable, since I know that I’m captive to a burden which I may have to drag with me for the rest of my life. I am ticked off at this slog, but it’s my slog. Thankfully I’ve found some fellow sloggers. We’ve all borne
our heavy PMR carts with stiff yokes, unrequested, and definitely undeserving. But we’re carrying on, giving aid and comfort to our fellow sufferers on this shared journey through the muck. We collectively curse the setbacks and celebrate those small victories of dry flat patches on our PMR paths—and relish our dreams of neither muck nor cart nor path at all.

ACKNOWLEDGMENTS
With grateful thanks and affection, I dedicate this article to all PMR victims and especially the over 4,000 members of the Facebook PMR-Polymyalgia Rheumatica Support group (https://www.facebook.com/groups/PMRpolymyalgia/). Their frustration and suffering with this obscure autoimmune disorder have inspired me to share from my own journey so as to raise awareness, promote understanding, and encourage research. General patient information on PMR can be found here (https://www.rheumatology.org/Portals/0/Files/Polymyalgia-Rheumatica-Fact-Sheet.pdf), from the American College of Rheumatology. I also thank the anonymous PMR patients and family members who assisted me with my research and writing.

DATA AVAILABILITY STATEMENT
Research data are not shared.

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How to cite this article: Paalman MH. My new normal: A patient’s perspective on polymyalgia rheumatica. *ImmunoMedicine*. 2021;1:e1010. https://doi.org/10.1002/imed.1010