Being a case report: Lessons learned

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Linda could not go outside or tolerate even very dim house lights. If we tried to go out at night, headlights clobbered her…. We lived like vampires.

Unfortunately, my family and I have had a lot of interactions with physicians of various stripes over the years. For details I refer you to prior editorials.[1,2] My wife and I, in particular, have been patients far more frequently than we or Care First would like. The physicians who have treated us have ranged across the board in personality, skill, confidence, empathy, self-denial, devotion to the patient's well-being, and their own desire to deal with tough medical challenges, along with a host of other variables.

I'd like to share with you an abbreviated case report that highlights some of these variables in action, along with some lessons learned along the way.

Now, I've always said that if there's one thing you never want to be, it's a case report. Not too many case reports discuss nice, easy illnesses that patients have happily endured. No, most case reports cover rare, unheard-of conditions, bizarre complications, or some weird element of common pathology or the occasional unexpected cure from an atypical treatment.

This case report is no exception. It also just so happens to center on my wife, Linda.[3]

Presentation

Let me start with the highlights. Linda was at work one day when she felt a sudden stabbing pain in her left eye that evolved into persistent eye and facial pain on the left side. She had no apparent rash, neurologic deficits, fever or other symptoms. She thought she had sinusitis, which she had never had before. I didn't think so, but otherwise was at a loss to explain it. I recommended she visit our internist and went off to a speaking gig in England. Four days later, our internist gave her a prescription for Acyclovir (Zovirax) and referred her to an ophthalmologist. Unfortunately, it was too late for the antiviral to control the herpes zoster infection. She was subsequently referred to a specialist to manage the corneal lesions that were decreasing her vision. Along the way Linda also became exceptionally sensitive to light, which triggered severe left-sided head pain.

Indeed, this symptom was profoundly debilitating. Linda could not go outside or tolerate even very dim house lights. If we tried to go out at night, headlights clobbered her. Even with eye patches, 99% light-absorbing sunglasses, floppy hats covering her eye, and combinations of all these, Linda was still utterly debilitated by any photon. We lived like vampires. These symptoms went on for more than a year during which we saw many specialists, who displayed a wide range of reactions to us and the mysterious illness they simply could not understand.

Seeking treatment

For example, early on we tried to make an appointment with a well-known ophthalmologist, who told us on the telephone not to bother, as there was nothing to be done in such a case. This was crushing (and ultimately incorrect). There are ways to help patients without making them all better.

Our internist next referred us to a highly regarded headache specialist, who was very

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nice and self-assured—just determined to decide what drug, among the vast armamentarium, would "knock this out" most quickly. Linda was serially given multiple headache treatments, mood stabilizers, antidepressants, etc. While she got all the side effects of the medications, she got no improvement in her condition. This specialist's confidence of early success was misplaced; while we received a temporary reprieve from the anxiety, at least, it returned with the failure to find a solution. As one last desperate try, this physician prescribed high-dose, "pulse" steroids for five days. There were lots of weird reactions: Linda developed profound fatigue and severe bradycardia to 35 bpm. Lo, and behold, the treatment worked. Her symptoms resolved for about three weeks, but then they returned. The treatment was so toxic that, given the short period of relief, it did not seem worth trying again. Well, our headache specialist was out of bullets.

Our cornea specialist had a nice, posh office with coffee and chocolates, a very organized and smooth-running practice, beautiful technicians … you get my drift. He "focused" on the cornea treatment and assured us he knew what this "syndrome" was. He had seen it before and it would get better in six to 12 months. Wow, were we happy. Every two to three weeks we saw him for the same exam and usually a minor treatment dose adjustment. He was very controlling and ordered in his approach. He did not like the fact that we were reading and getting ideas and looking for other treatments and asking difficult questions. After about a year we mutually gave up, and he referred us to another ophthalmologist as even the corneal problems persisted. Actually, he "fired" Linda as a patient for making an appointment with his partner when he was unavailable. I doubt he ever knew what my wife's condition was about as no one else did, including those working at high level academic centers.

We get proactive

During the next several months Linda and I read everything we could find anywhere near the subject, and I talked to specialists of all kinds at my institution. I got many ideas from my unofficial consultants, most involving ablating parts of the trigeminal nucleus. This sounded like a last desperate step. I wrote letters to specialists at other U.S. centers, looking for anyone who might recognize this condition. Ultimately, we got a detailed letter and telephone call from a physician who actually had seen some patients with symptoms at least resembling those of my wife. She provided a long list of treatment options, many of which Linda had tried without success. But there was one treatment on that list that had been given only a brief, almost dismissive, mention in papers and articles: superior stellate ganglion anesthetic injection.

Success

Ultimately, it was this procedure that was performed and which miraculously and immediately resolved Linda's photophobia and headaches! Initially, the treatment lasted only three days, but it has been effective for longer periods each time it has been performed. A successful injection is marked by a profound Horner's sign.

We have found a great empathic, brilliant, but down-to-earth anesthesiologist who has hit the spot for injection every time. My wife is now well over a year out from her last treatment. She still has trigeminal neuropathy, but that is typical and relatively medically manageable. She was written up as a case report by the anesthesia group at our current, and hopefully final, treatment center.[3]

Lessons learned

So what did we learn though this experience? I believe we have come away with five key lessons:

1. Physicians usually know when they are in over their head with a patient's condition, but often they don't, and that can delay patients from finding someone who can help them.
2. High physician confidence early in treatment can be a great boost to a desperate patient, but it can result in greater anxiety, frustration and anger if ultimately nothing helps.
3. Beware of a healthcare provider who protests when a patient (particularly one with a medical background) researches the causes and/or treatments of his or her illness or seeks other physicians for additional help or guidance.
4. Being told that nothing can be done to treat your illness should not end the matter. There are a great many physicians in this country in every specialty with widely varying experience. Be prepared to hunt beyond your normal range if local physicians are not knowledgeable about your medical problem.
5. Ask questions about your condition and discuss the treatment plan and your expectations with your physician. Don't be too intimidated to discuss your reading of the medical literature if you have the background to understand it reasonably well.

My best suggestion is to do everything within your power to avoid becoming a case report. The notoriety is probably not worth it. But if you do become a case report, hopefully your experience can benefit another patient with the same strange condition.

References

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3. Sinofsky A, Sharma T, Wright T. Stellate ganglion block for debilitating photophobia secondary to trigeminal post-herpetic neuralgia. *Pain Pract.* 2016; July 5 Epub ahead of print.