This is a story about a patient I'll call Vickie and a rare type of very severe headache called hemicrania continua. But mostly it's about the lessons healers learn when seeking a healing path for their patients. After 30,000 outpatient visits as director of the Headache Clinic, Vickie taught me something new about headache.

I like this story because it's about Vickie—who has been my patient for years—and her bravery and perseverance. People who suffer from headaches are often misunderstood, perhaps as often by physicians as by family members and friends. I think I understood how much pain Vickie was having, but at first I didn't understand her diagnosis. A doctor has to get both right.

When you tell someone you have a headache, they assume that it's the same kind of headache that they have had. Of course, it isn't; yours may be a migraine, theirs a simple fatigue headache; yours may be a brain infection or tumor, theirs may have been too much red wine the night before or an argument with their boss. In any case, when people heard Vickie's story, they tended to think it couldn't be so bad. After all, we've all had our little headaches, right?

But Vickie's headache is not migraine and it isn't exactly cluster headache; it's somewhere close to a rare condition called hemicrania continua. It's a very rare, severe form of headache; only a few hundred cases have been described well in the neurology literature. But what is most important for Vickie is that when she says that she hurts, almost nobody gets it. They don't get how severe her pain is; and I didn't get the right diagnosis at first.

Vickie retired this year after a career teaching in the public school system. She is obviously gifted, even among teachers, for her understanding of children. So it was unfair, after so many years of understanding her students, that she suffered from an illness that others find difficult to understand.

Vickie is bright, funny, and a joy to be around. When overwhelmed by pain, she would have panics of fear that everything was spinning out of control, and that the headaches would never go away. This was a dark side to her life. The pain was agonizing, crushing, but it wouldn't go away. This was a dark side to all, we've all had our little headaches, right?

CAUSES OF HEADACHE

Many people think the role of a doctor is to listen, to understand, and to be compassionate. But more important than this: the role of a doctor is to get the right diagnosis.

There are hundreds of causes of headache; genetic, endocrine, toxic, infectious, neoplastic, psychological, vascular. Vickie has a rare condition that illustrates the importance of getting the diagnosis right: hemicrania continua, a type of headache that responds only to indomethacin.

The treatment with indomethacin is so important that it is actually the defining criterion for having this rare headache: if your headaches vanish magically when you take indomethacin, then you have a headache in the family of hemicrania continua. If they don't, then you don't.

Hemicrania continua is almost always a primary headache, meaning that it is not caused by a brain tumor, infection, or other cause. The International Headache Society offers a detailed list of criteria defining this headache. If you translate the medical jargon, hemicrania continua is basically a headache on one side that never goes away, at times is really severe, and is associated with a runny nose and red eye on that side; responds completely to indomethacin; and isn't some other kind of headache.

A DIAGNOSTIC QUESTION

But Vickie's case was not typical of a hemicrania continua sufferer. She had pain-free periods. She didn't have much in the way of a runny nose and red eye; and she responded to injections that were reserved for severe cluster headache and migraine.

One day she came in for a regular checkup—when I check her blood pressure, examine her for signs of vasoconstriction, and write a new prescription for her injections.

However, this time was different; I don't know why. Vickie was talking about her recent retirement from the school system, how her life had changed, how good things were, and the only difficult thing (as if it were a small thing!) were the shots she took every night, and how that wasn't so bad, and how lots of people were much worse off. As she talked, my mind wandered off to her headaches being on one side only . . . “Vickie, you have ever been on indomethacin?”

Her old medical records were voluminous; I thought about going through them. But then, I realized we needed to try indomethacin at high doses, even if she had been on low doses in the past. She didn't have hemicrania continua exactly; but if you eliminated a lot of the criteria, she did have headaches on one side. So I wrote the prescription for indomethacin.

The next time she came in—no headaches! She definitely had one of the rare headaches that are indomethacin responsive. And she had certainly taught me something about the importance of persistence and courage.

There is much more I would like to say about Vickie. And, much more to say about the importance of getting the diagnosis right for people like her. Thanks to her courage, I'm a little better at doctoring headaches than I was before I met her.”

The North Carolina Comprehensive Headache Clinic provides outpatient-neurological evaluations and comprehensive treatment for the patient with headache, facial pain and neck pain. New patients are welcome. For information or to schedule an appointment, contact:

NORTH CAROLINA COMPREHENSIVE HEADACHE CLINIC
2501 Atrium Drive, Suite 400
Raleigh, NC 27607
Telephone: (919) 781-7423
For more information, please visit our website at:
www.ncheadache.com
Click through to educational links with our national organizations, including the American Academy of Neurology, the National Headache Foundation, and the American Council on Headache Education.