

PERNICIOUS ANEMIA

By **Thomas Heath** February 22, 2000

Only later, much later, as I sat across the desk from yet another medical specialist, did I connect the dots and realize how close my bewildering illness had come to killing me.

For months, years even, I had found ways to rationalize, overlook or ignore a bizarre series of seemingly unrelated symptoms. Tingling in my arms and legs? A rushed weight-lifting session, I figured. Forgetfulness and loss of concentration? I wrote them off to onrushing middle age. After the tingling worsened into numbness, I still never put it together with other signs of trouble: irritability, fainting spells and occasional loss of bladder control. Not even when my tongue turned raw and started to bleed.

Even now, four years after my first baffling hint of trouble and eight months after doctors diagnosed an uncommon but treatable form of anemia, it is hard for me to admit how long I took to realize that my life was in peril.

In hindsight it all seems so obvious.

I was jogging down a road near my in-laws' home in Arizona when I first felt a numbness in my hands and lower legs. Had I overdone the weight lifting the night before? Were decades of jogging and basketball finally taking their toll?

That same year, I began having difficulty with memory. I was entering my forties and thought middle age was causing me to forget names, dates and places. While covering the 1996 Olympics in Atlanta as a sportswriter for The Post, I kept getting frustrated that I could not recall the words "Olympic Torch Relay," and instead referred to it in conversation as "that marathon." Friends became noticeably uncomfortable as I stumbled to complete a sentence, unable to summon up the next word.

My ability to concentrate also deteriorated. I gradually stopped reading books and watching movies, even though they are my favorite pastimes. My wife, Polly, thought I might be getting Alzheimer's disease.

By the end of 1998, I had begun running on a treadmill at the gym instead of running outdoors because I kept stumbling on my numb feet. It felt as if my legs and feet were constantly asleep. After a while, I was losing my balance even on the treadmill and quit running altogether.

By last spring, I was getting sick almost weekly, and losing control of my bowels and my bladder. My tongue was raw and bled easily. I occasionally fainted. I was increasingly irritable, exploding in frustration at the most trivial situations in everyday life. I was losing concentration and took several weeks off from work to try to pull myself together. During that time I saw a

psychiatrist, who said there might be a chemical imbalance in my brain. I stopped seeing him after three or four half-hour visits, during which we mostly talked about antidepressant medications.

I still hadn't made the connections among my various difficulties. A routine physical in late 1998 had only shown an above-average level of cholesterol and a deficiency of folic acid, a B vitamin found in green, leafy vegetables such as spinach. On my doctor's recommendation, I started taking folic acid supplements.

Walking became so difficult that I finally went to see an orthopedist. He took X-rays and a magnetic resonance imaging (MRI) scan and gave me steroids that he said would reduce inflammation in my legs. But the X-rays showed my knees were fine, the bones normal. The orthopedist said something else that struck me as odd: He told me to take a hot shower every day. I realized that I had inexplicably stopped showering daily.

After two months, he asked me if my legs felt any better. Same numbness, I said. He referred me to a neurologist, and I began to panic. My mind raced with thoughts of muscular dystrophy, multiple sclerosis, Lou Gehrig and the slow death he suffered from amyotrophic lateral sclerosis.

On the wall in the neurologist's waiting room there was a poster describing milestones in the history of neuromuscular disease--and a photo of Gehrig. This was it, I thought. I was about to be weeded out as a weak member of the species by the process of natural selection. To my relief, the neurologist tested my muscles and pronounced them okay. But when he asked me to close my eyes and walk a straight line, I almost fell over. I couldn't tell where my legs were without my sight.

"We want to get to know you better," I remember him saying. A series of unpleasant tests followed, over the next few weeks, to measure the nerve activity in my legs and arms. These included getting repeatedly stabbed by a tiny needle that shot electric impulses into my feet and hands. From the results, my neurologist said I had a "peripheral neuropathy," which meant the nerves in my extremities were malfunctioning.

Early last summer, I was sitting with Polly when the neurologist told us that we might never find the cause of my trouble. But he had a long-shot hunch. Once every five years or so, he said, a patient comes through his office with similar symptoms and is found to have a deficiency of vitamin B12. He called the lab where I had undergone a recent blood test and told them to fax him the results while we waited.

Answer: low B12.

He immediately referred me to a hematologist-oncologist, a specialist in cancer of the blood and bone marrow. Within hours, Polly and I were in the specialist's office. I was scared to death. I thought I might have dodged the muscle disease only to face bad news from the sober-looking cancer doctor sitting across from me.

He said I had a disease called pernicious anemia. I didn't like the "pernicious" part.

"I think this is going to be totally correctable," were the next words out of his mouth. Polly and I exchanged reassuring glances.

The hematologist reeled off the symptoms: poor balance, unusual gait, diminished mental ability, sore tongue, lack of concentration, overall fatigue. Every cell in my body was affected, he told me. He said that just a few decades ago, nursing homes were full of pernicious anemia victims who were paralyzed and demented and waiting to die.

As I walked back to work from the doctor's office that afternoon, I was overcome with sadness that something was secretly wrecking my body. It was the only time I felt sorry for myself.

Pernicious anemia is caused by a person's inability to absorb vitamin B12, which is essential for the normal metabolism of the nucleic acids found in all living cells. Vitamin B12 is also essential for nerve development and the formation of hemoglobin, the oxygen-carrying protein in red blood cells. You can't live without B12, so the disease is fatal if left untreated. A person requires only a minuscule amount of it per day--less than one-millionth of a gram (a microgram). Red meat and dairy products are chief sources of B12, making strict vegetarians more susceptible than meat-eaters.

"It's important for the formation of all cells," said Virgil Fairbanks, professor emeritus in internal and laboratory medicine at the Mayo Clinic in Rochester, Minn.

At some point in the past decade, Fairbanks said, my autoimmune system began to malfunction. Instead of producing antibodies to fight only foreign threats to the body's health, my autoimmune system had mistakenly identified one of my own proteins as a threat and attacked those. That prevented the protein from producing a substance called "intrinsic factor" in the stomach's gastric juices. Intrinsic factor binds with B12 and transports it to the lower bowel, where it is absorbed into the bloodstream.

Chronic bowel diseases such as Crohn's disease can also damage the lower part of the small intestine and prevent the absorption of B12. Rarer still is a tapeworm-like parasite found in undercooked freshwater fish that causes pernicious anemia by absorbing the B12 in the stomach before it gets to the bloodstream. The disease increases the chances of contracting gastric and colorectal cancers, which can be fatal if not caught early. Pernicious anemia is also seen with Graves' disease (a thyroid disorder), thyroiditis and myasthenia gravis (an autoimmune disease that causes muscle weakness).

Pernicious anemia is believed to be hereditary, most often found among people of Northern European descent, according to Fairbanks. It strikes about one in 10,000 people, generally after age 30. But it has been known to attack all ages and races, Fairbanks said.

Fairbanks said my body probably stopped producing intrinsic factor at least five years ago. The human liver normally stores 1,000 micrograms of B12, which is more than a five-year supply. It is unclear how depleted the body's B12 stores must become before the onset of symptoms, Fairbanks said, but he believes they have to be almost exhausted.

The deficiency is diagnosed through blood tests and a bone marrow biopsy. A painless test called a Schilling test, which measures B12 in the urine, confirms that the deficiency is caused by a loss of intrinsic factor, rather than bowel disease or tapeworms.

The dangerous part of pernicious anemia comes when its victims fail to recognize that the symptoms are serious enough to warrant a trip to the doctor. In my case, I thought I was just getting old and my knees were shot. In retrospect, doctors said, the folic acid supplements I was taking may have helped mask my pernicious anemia. The enlarged red blood cells that are evidence of pernicious anemia sometimes are shrunk by folic acid.

Usually, but not always, the disease shows up as a low B12 concentration in the bloodstream. But the blood test typically ordered during a routine physical does not check for B12.

"People don't seek medical attention because the symptoms appear mild at the start," said Dennis Gastineau, a hematologist at the Mayo Clinic. "The problems can be going on for many months or even years before people decide to see a doctor."

The body loses feeling in the feet and hands because the lack of B12 affects the coating on long nerves to the extremities, slowing the nerve impulses, according to Gastineau. The raw and bleeding tongue develops because we slough off the cells that make up the skin, tongue and mucus membranes inside our cheeks and there isn't B12 to form new cells and replace the skin. Without B12 feeding the cells in the brain, it also begins to degenerate, resulting in impaired memory, depression and psychosis.

"It may mean increased irritability, memory loss and changes in emotion," Fairbanks said.

And yet, for all its many ways of causing harm, pernicious anemia is surprisingly treatable.

Once the diagnosis is confirmed, daily injections of B12 into the bloodstream bring immediate improvement. The shots do not cure the underlying autoimmune defect, but they correct its most dangerous symptom by restoring the body's depleted supplies of B12.

After the body's B12 levels are restored, the shots must be continued monthly for life. Full recovery is a slow process and depends on how far the disease advanced and how much nerve damage it caused.

It can take up to a year to get the nerves in the feet and legs back to normal--but progress is not a sure thing. My neurologist told me that the extent of my recovery from this point on "is up to the gods."

My hands seem fine now, but my legs and feet are still numb and have weak reflexes. They feel like they're asleep. I am able to jog again, but very slowly and with my eyes focused on the ground directly in front of me. Otherwise I stumble. Before I got sick, I ran four marathons and averaged about eight minutes per mile. Now, I run much shorter distances, at about half that speed.

I haven't had any problems with my bladder and bowels since I began B12 injections. My thyroid is normal and my cognitive functions seem okay. I know I don't lose my temper as often as I used to, and I have returned to reading books and watching movies. I am interested in more things, too, although I still seem to have more trouble than usual remembering names, words and appointments. My doctors suggested IQ and memory exams to test for damage, but I choose not to know.

My hematologist suggested I see a psychiatrist to help me adjust to any long-term physical restrictions that I may have. I see him once a week.

Even after my vitamin B12 deficiency was discovered, the diagnosis was far from simple. Because my Schilling test had not indicated a lack of intrinsic factor, my hematologist ordered a colonoscopy, endoscopy and other exams to see if the cause of my anemia lay elsewhere. The doctor said this was important because pernicious anemia could be just one manifestation of some sinister disease that might cause problems for me in the years to come. That took weeks, while he and a gastroenterologist looked for a chronic bowel disease or stomach cancer. When they turned up nothing, a second Schilling test confirmed, to my relief, that I had classic pernicious anemia.

Pernicious anemia was a big killer before treatment--with booster shots of vitamin B12--was developed. Untreated, it can kill by slowly destroying people's organs; immobility due to weakened limbs also makes patients more susceptible to life-threatening pneumonia.

"There's a reason it's called pernicious," Fairbanks said.

The disease was named in the 1870s by a German doctor, and it continued to claim victims well into the 20th century. In developed countries today, pernicious anemia is rarely fatal, although effective treatment is sometimes delayed, as in my case, by overlooking early symptoms.

During the 1920s, scientists discovered that if they whipped calves' liver into a "liver shake" and a patient drank a quart per day, the patient would absorb enough B12 to stave off the symptoms of pernicious anemia. Treatment progressed and in 1934, those same scientists--George R. Minot, William P. Murphy and G.H. Whipple--shared the Nobel Prize in medicine for their research on pernicious anemia. Shots of synthetic vitamin B12 became available in the 1950s.

I think about those men during my monthly visits to the hematologist-oncologist for my B12 shot. I see leukemia patients with their arms tethered to tubes feeding them chemotherapy. There aren't a lot of happy faces in that office. That's when I feel very fortunate. Although my body, my life and my marriage were slowly unraveling because of this insidious disease, they have been repaired.

When I think back on the last four years, what makes me saddest is knowing how long it took to realize that something inside me was stealthily ruining my life. Only in hindsight does it all connect. Except for the numbness, my baffling ailments seemed to come and go. It's easy to shrug off memory problems as a fact of age. I had a physical, but it turned up nothing extraordinary. When I saw a doctor about my bleeding tongue, he attributed it to a fungus and gave me something to rinse my mouth with. Maybe I should have visited the orthopedist as soon as the numbness started, but even he might have missed the underlying cause.

I'm not a stoic, but despite all this I find it hard to feel sorry for myself. After all, I was lucky enough to acquire a disease that is essentially curable. Compared with other possible causes of my puzzling symptoms--Lou Gehrig's disease, chronic bowel disease, cancer--a shot once a month and a little numbness in my feet don't seem like much.

Tracing an Uncertain Path From Symptom to Diagnosis

4/24/2018 PERNICIOUS ANEMIA - The Washington Post

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Medical diagnosis, as doctors and patients learn daily, is as much art as science. It is based on symptoms, medical history and test results, of course, but also on intuition and hunch.

One tool that can help patients pin down a diagnosis or decide where to look next is an algorithm, or step-by-step "decision tree," based on initial symptoms and a series of yes-or-no questions. Warning: Such guides are hardly foolproof, and many medical conditions involve vague, overlapping symptoms.

Here's how one set of diagnostic "trees"--from the American Medical Association's Family Medical Guide (Random House, 1994)--might have worked for five symptoms Thomas Heath experienced (see cover story).

* NUMBNESS AND TINGLING. The patient's "no" answers to specific questions would have ruled out possibilities such as a temporary "pins and needles" feeling, osteoarthritis, carpal tunnel syndrome and stroke--and led him to "consult your physician."

* **IMPAIRED MEMORY.** Because the memory loss did not involve a head injury, use of alcohol, seizures, a prolonged fever or surgery, the tree would suggest that "emotional stress may be affecting your ability to concentrate." It would direct him to chapters in the book dealing with depression and anxiety.

* SORE TONGUE. The tree would rule out dental problems, including gum disease, cold sores, yeast infections and allergic reactions--and end up with the "consult your physician" guideline.

* **LACK OF BLADDER CONTROL.** A series of "no" answers would lead the patient again to the prudent but inconclusive "consult your physician." Alternative guesses would include stress incontinence or irritable bladder (if a woman) and enlarged prostate (if a man over age 60).

* **FAINTING.** This turns out to be the most complicated, and revealing, of the five "trees." After a series of 10 "no" answers (ruling out high blood pressure, heart problems, heat exhaustion and low blood sugar), a single "yes" branch--"Do you feel inexplicably tired?"--would lead to an intriguing conclusion: "You may have a form of anemia." By checking the indicated page in the AMA guide, the patient would learn about several types of anemia and come across this telling clue:

"Other causes of anemia include severe deficiencies of vitamin B12 or folic acid. . . ."

--Don Colburn

0 Comments

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