HELP! Why Can’t Anyone Diagnose This Vexing Cough?

As people living with cancer know, the disease likes to find gray areas and create unusual health problems that aren’t easily solved.

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Among the countless new — and unwanted — experiences that cancer escorts to one’s doorstep are mysterious ailments. Naturally, as all of us age (whether one be cancerous or benign (read: lucky)), these seemingly difficult to diagnose problems can crop up. The issue for those of us with cancer as constant companions, however, is that we never know whether mystery problem X is merely a nuisance or cancer in one of its innumerable disguises. And once one has had cancer for any length of time, one naturally has to assume — or at least strongly consider — that the problem is indeed cancer-related.

Thus, I find myself, nearly a decade after my initial cancer diagnosis, with a vexing problem that no one seems to be able to address. More specifically, roughly around the time my cancer was most unwelcomely ushered into my daily existence, I developed a regular cough. This cough announced itself principally when I was sleeping, which is of course the perfect time for an already horrendous sleeper to be accosted by such an ailment.

Because the problem, initially, seemed to be one of me while supine, it suggested that it might be a simple case of acid reflux, or, for those who love acronyms (and who doesn’t?), GERD, which needless to state stands for GastroEsophageal Reflux Disease. (I personally prefer to call it simply reflux because (i) I find pronunciation — not to mention spelling — of gastroesophageal — rather challenging and (ii) my dance card of diseases is pretty much already full what with cancer and all, which is quite the jealous illness.)

Yet various primary care doctors (i.e., GPs — another acronym for the reading public), otolaryngologists (or ENTs, for one more) and gastroenterologists who concluded this was merely reflux, ultimately did what all doctors initially confronted with this do — prescribed anti-reflux medicine. When that naturally did not solve the problem, the bolder (and less proactive) among these MDs did what all doctors seemingly do — upped the dosage. But, of course, no relief was forthcoming. I continued to cough away night after night (or, since I am a huge proponent of naps, afternoon after afternoon as well).

At this point, having become rather discouraged, I reluctantly raised the issue with my oncologist.

Upon hearing of this problem, she assured me that this was likely just allergies, which as I was to then learn, were another bonus health problem that one gets with my form of leukemia. Since this is merely a blog post, I do not have the space to enumerate all, but add this new problem caused by cancer — which of course is a bit of a problem in and of itself — to skin cancer, colon cancer, susceptibility to mosquito bites (yes, really) and a general inability to combat even the most mundane of illnesses.

Armed with this new, depressing information, I eventually made an appointment with an allergist to be poked with countless irritants with strict instructions not to scratch. Although they did all seem to irritate me, that apparently was not enough to conclude that I was allergic to anything. Nope, allergies did not seem to be the problem.

After a couple more years of dorsal-induced hacking, I finally decided to try again. This time I went to see a pulmonologist, which is a fancy-sounding term for a lung doctor. Let me just say that people with cancer, if I may generalize, are not too keen on seeing pulmonologists. For one thing, these doctors love to take X-rays, and as someone with one form of cancer and a laundry list of other cancers that I am a candidate for at no extra cost as a result of my current malignancy, I am not overly enthused about exposing myself to radiation. Particularly when I have recently had a chest X-ray already.

But for some inexplicable reason, doctors — who themselves do not actually take the X-rays (or maybe even read them) — are always convinced they should be redone as whatever doctor took them previously must not have known what she was doing (or, more precisely, the lab techs from which she ordered them were doing). Similarly, I was required to have more blood drawn — a regular occurrence in the life of a person with blood cancer but one I would, perhaps surprisingly, like to engage in less frequently — to prove that I was not allergic to anything. Spoiler alert: I was just as un-allergic (non-allergic? allergen-free?) as the allergist had found.

Having exhausted all of the tests I had already exhausted in the past, the pulmonologist decided a good use of my time and resources would be a sleep study. Although I was able to take the “test” from the comfortable confines of my own bed (which, I should say, was made into a poor man’s Craftmatic Adjustable in the off-chance that all of the conclusions of no reflux were incorrect and thus sleeping downhill might cure this recurring cough by inserting a few blocks under the headboard), I nonetheless had a miserable night’s sleep. I wonder if it could have anything to do with the circulation-killing device clamped to my finger or the fact that it was wired to my chest underneath my shirt. I am a bit idiosyncratic in many of my behaviors, and perhaps this is one of them, but I generally find that I do not sleep well when wired like an undercover narcotics agent on the job.

Perhaps not surprisingly, the sleep study found that I have trouble sleeping. More precisely, I had a number of disruptions during the night which was enough, in this doctor’s experienced view, to conclude that I have sleep apnea. Fortunately, rather than prescribing a frogman-like CPAP machine, he recommended a mere oral appliance that I could get from any sleep dentist. Did you know there were dentists who specialize in sleep? Neither did I; I thought they worked with teeth. I

am so old-fashioned in my thinking.

But before I could run off to this previously unknown doctor of teeth or sleep or whatever, I consulted another doctor who is also board certified in sleep and, in my view, quite knowledgeable. This other doctor, in consultation with my GP — who, by the way, is himself a pulmonologist as well but he lost interest in my cough after a couple visits — highly doubted the results of this "study." So here I am, caught in a battle of experts. I do not know whom to trust, but I honestly think no one really knows what's happening.

Part of my negativity about this new, unnecessary diagnosis is that I do not think that any of the doctors are really hearing what I am saying. This is, admittedly, at least partially my fault as I find it challenging to articulate exactly what the problem is beyond the coughing aspect. Hence, these doctors are left without all the dots connected for them by yours truly. But, since I am usually asleep when the fireworks begin, it's a bit hard for me to describe the events as they play out. The sleep study, I gather, was to help fill in these gaps but since now there is a doubt about its reliability I am even more frustrated than I was when merely coughing. Now I am coughing and exasperated.

The real problem as I see it, and of course I am no doctor — merely a person living with the consequences of a loathsome disease (or possibly two if GERD is still on the table) — is that this issue may well lie in the interstices of medical disciplines that cancer loves to exploit. In today's highly-specialized society we assume that there is someone to deal with every particular issue. But, most regrettably, cancer does not seem to feel that its reach should be confined to the training received by the oncologists of the world. It likes to find the gray area between diagnoses — and diagnosers — and wreak havoc. And it's not the doctors' fault: They can't possibly know all there is to know about everything, as much as we as patients wish they did.

So where am I? Between coughs and fits of annoyance, I will try to make an appointment with a sleep dentist. I am far from convinced that this will solve any problems, of course, but I appear to be running out of options. And since no one but the author of this post seems to be sufficiently concerned about the resolution of this problem, I am going to cautiously pursue what appears to be the only avenue open to me. I am supposed to report back to the pulmonologist in three months time, around which time I wouldn't be surprised if there were another exasperated blog post on this site.

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