

It's More About Cancer Than I Thought

Lung cancer blogger Dan Wonser finally got to the bottom of his lockjaw and related jaw pain mystery.

February 12, 2024 By [Dann Wonser](#)

Friends and Family,

We've finally gotten to the bottom of my lockjaw and related jaw pain mystery. On Genevieve's and my most recent visit, my oncology dentist spotted a hole in my gum. That led to a diagnosis that brought me to tears for only the second time ever in a doctor's office:

osteonecrosis.

A CT scan confirmed that my jawbone is being eaten away.

I was aware that osteonecrosis was possible because I have been on a bone-strengthening drug (to replenish the parts of my spine that cancer ate away two years ago). It's ironic that bone death is a potential (but uncommon) side effect of a drug (Xgeva) meant to strengthen the bone, but there you are. When we first heard the diagnosis, I had visions that something like this was coming next: My jaw would literally come unhinged and fall off.

Fortunately, it doesn't look like that is going to happen. The osteonecrosis is possible because of the Xgeva, but it also requires an infection. The infection came because of the exposed bone, and it is the infection that's eating away at the bone. If antibiotics can get rid of the infection the osteonecrosis can be stopped or potentially reversed. There is a miniscule chance it becomes untreatable, which would result in cutting out a section of my jaw and replacing it with bone from my leg. That gives me added motivation to make sure treatment works.

The path is not straightforward, however. The infectious disease doctor is only guessing at which antibiotics to use without a bone biopsy, and I can't open my mouth wide enough to get a bone biopsy from the exposed bone. If the oral antibiotics work well enough to open my mouth more, chances are there won't be enough infection left in the bone to culture. As an added bonus, my tongue has rubbed raw against the exposed bone, making it painful to talk or even chew a slice of cheese.

This all sounds like a downer, but there is an upside. I started antibiotics Monday and the pain in my jaw has already subsided. Now I can open my mouth wide enough to get one finger in. Progress! If these antibiotics stop working, the next step is to have a central line put in my arm

and have home infusion of a different type of antibiotics daily for 4-6 weeks.

Genevieve and I have been trying to get to the bottom of this since the pain began in October. Since then, we have consulted with no less than ten medical/dental professionals in pursuit of an answer. At every step, we had to push to get appointments and not allow them to put us off for a couple weeks. When I was referred to another professional, each time I got the phone number of that office and called them immediately. I have found that if a referral is made it can take days or even weeks before that office gets around to calling. You have to be your own advocate and push for care when you need it. Had we not pushed, we would be three or four steps back and still waiting for answers. I have a lot of compassion for people who don't know how to navigate the system and get stuck waiting for care. It can make all the difference.

Thank you all for your amazing support. I couldn't do this without you.

Love,

Dann

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