



I Wish I'd Known What PI Could Do to My Teeth

By Ilana Jacqueline

ABOUT A MONTH ago, I made myself the most fabulous looking Greek gyro. I was so excited to dig into this soft-baked naan I'd bought, but when I took the first bite, something just felt wrong. I cut my lip. How did I manage to cut my lip on soft-baked naan? Then, I looked in the mirror, and to my immense horror, I saw my own personal nightmare staring back at me.

Now let me stop here and preface this by saying my body has been through some incredible things. I've had more procedures and surgeries than I can count. I've been cut open and rearranged and had bones shaven down and organs pulled apart. I've had surgeries without anesthesia. I've had stitches pulled out of my eyeballs. But, dental work is my nightmare.

One of my front teeth had split right up the middle, and had cut my lip. I looked like a hillbilly. It was the fourth front tooth that had broken off this year, and I now had a row of completely different-sized front teeth. There was no way of hiding it or telling myself it could be shaved down or matched to the worst one of the set. No, this was the nail in the coffin. These teeth were now going to have to be replaced.

I stood in front of the mirror for a half hour thinking: "No, this isn't happening. This isn't happening." Then, I called my mom, tossed my gyro and made several dental appointments. After seeing two specialists, I was told my teeth were much worse off than I could have imagined. I needed six teeth to be removed right up to the root and covered with caps. If I didn't get this done, and

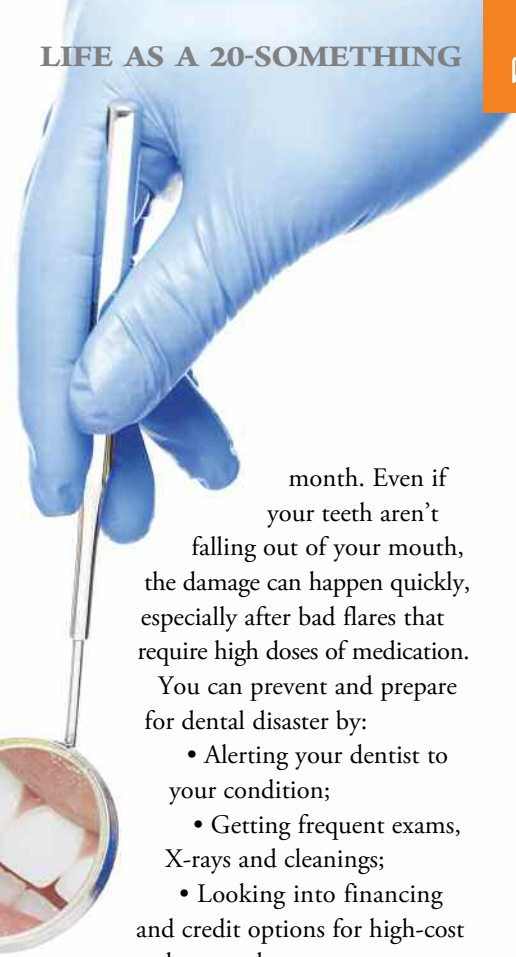
soon, my six front teeth would continue splitting, cracking and potentially even falling out on their own.

During the early months of 2017, I'd had a major infection that required treatment with intravenous antibiotics for several months. I'm sure there was some mention of "this may cause cavities or enamel weakening" by an immunologist at some point. But I was a little more worried about the infection putting a complete and total stop to my daily life. I didn't realize how at risk I was as a primary immune deficiency (PI) patient. I didn't really think the years of antibiotics and medications taken for my disease would actually cause dental damage.

Even so, I was diligent about my dental care. I'd had three cleanings last year. Could my dentist actually miss a sign that my teeth were in serious crisis? As it turns out, he could, and boy did he. I was told we could have caught the damage even earlier if my previous dentist had been aware of my condition, knew how much medication I had been on and had taken regular X-rays — more regular than just once a year.

I was fortunate to be able to save the roots of my teeth, so I did not need full implants. This saved me an astronomical amount of money, pain and potential complications. However, for most PI patients, the destruction to their teeth and gums doesn't get attention until it becomes an unsalvageable, bankrupting mess.

Consider this your cautionary tale. Pick up the phone, and make an appointment to get an extra cleaning and X-rays this



month. Even if your teeth aren't falling out of your mouth, the damage can happen quickly, especially after bad flares that require high doses of medication.

You can prevent and prepare for dental disaster by:

- Alerting your dentist to your condition;
- Getting frequent exams, X-rays and cleanings;
- Looking into financing and credit options for high-cost procedures such as veneers, caps and implants that you may need in the future; and
- Asking your dentist for specialty and prescription mouthwashes and toothpaste to help prevent decay.

It's more common than you think for PI patients to have major dental work, including dentures. There are many dental-based charities and financing options for extreme medical work due to disease progression. Preventive care is your best option for keeping your teeth healthy and strong. Invest in cleanings, good brushes and high-end toothpastes and mouthwashes. And, remember, you are not alone. ■



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