

Life as a 20-Something



Stop, Drop and Roll: Acting on Infections with PI

By Ilana Jacqueline

WHEN BUILDINGS BURN, you really start to get a feel for who people are. There are the victims, the fire-fighters, the spectators who scream “Why isn’t anyone saving them?” while they idly stand by — and, then, there are the people who do nothing. Because some people just like to watch the world burn.

So which one are you? I’m going to give you a strong suggestion: You should probably be the one fanning their flaming butt as they run out of the building. If I’ve learned anything from being a patient with a primary immune deficiency (PI), it’s that I should already be breaking out the fire extinguisher when I think I might be smelling, what I think could be, smoke.

Whether it was a sore throat or a hint of a sniffle — if I felt iffy at 9:30 a.m., by noon I could be ready for IV antibiotics. Long before I was diagnosed, when I lived in a world of constant bronchitis that would leave me practically delirious with symptoms, I knew that there was little time to waste when it came to sorting out infections. Just about everything I had would flow through my body, weakening every joint, leaving every mucus membrane dry. And while family and friends would look on at my spastic, quick-dialing of doctors, I had to learn to ignore the “you’re such an alarmist” comments and trust that

I knew the timeline for how quickly my barriers could crumble under fire.

By the time you’re in your 20s, it’s safe to say you’ve got a grip on the realities of your disease, so be calm and confident, and follow these tips for reaching clean air:

Think fast. At the first sign of an infection, skip ahead a few steps. What would you do if you’d be suffering for the last week like you’ve been suffering for the last hour? Would you call the doctor? Start on a medication you’d normally take for this kind of infection? Have a game plan ready to go.

Cast off judgment. So your roommate doesn’t agree that you should hit CVS for antiseptic wash at four in the morning? Well, her skin infections usually don’t turn to staph and then spread from one open wound to the next, do they? So what do you care about her “if I were you’s”? If you haven’t figured out by now that the typical instructions do not apply here, you’re going to have a bad time.

Get your doctors on board. If you’re working with a new physician, emergency room doctor or even just the unfamiliar urgent clinic staff, give them an elevator speech on immune deficiency and how it affects you. Not all doctors are familiar with PI, and they may need a crash course on how to get you better as quickly as possible.

Stay ahead of the curve. Sinus infections often find me at about three in the morning. Waiting until 9 a.m. to call the doctor is painful enough to start getting relief. It’s a good idea to have medications (or even just treatments like heat packs or other aids to make you comfortable) around the house, just in case. Similarly, if your infection seems particularly serious, you should also have your hospital bag with clothes, toiletries, lists of allergies and current medications ready to go.

Make sure your team is available. If your ENT doesn’t have same-day appointments, make sure your immunologist does. Those with immune deficiencies usually have several doctors they regularly see. Know which ones will be able to take you at the first sign of an infection, and focus on making appointments with them as soon as possible.

We’re not always in charge of the jerk bacteria and viruses that cause our “forest fires,” but we’re the only people who can stop them from spreading. ■

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