"My life is never going to be normal again." – The toll of antibiotic resistance

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SPEAKERS

Maggie Fox, Rosemary Bartel

Maggie Fox 00:01

Hello and welcome to One World, One Health where we take a look at some of the biggest problems facing our world. I'm Maggie Fox. This podcast is brought to you by the One Health Trust with bite-sized insights into ways to help address challenges, such as infectious diseases, climate change, and pollution. We take a One Health approach that recognizes that we're all in this together and everything on this planet — the animals, plants, and people, and the climate and environment — are all linked.

Rosemary Bartel wasn't worried when she went in for knee replacement surgery. She'd been through several operations before, but she ended up with a serious drug-resistant infection called methicillin-resistant Staphylococcus aureus (MRSA). It's a common infection caused by bacteria that resists the effects of antibiotics. Rosemary was one of 2.8 million Americans who get drug-resistant infections every year, according to the US Centers for Disease Control and Prevention (US CDC). These infections sicken many millions more people worldwide, and they're involved in close to five million deaths a year.

Rosemary has gone public with her experience in the hope of helping others. She's on the patient and caregiver panel for the LeapFrog group, a nonprofit healthcare patient advocacy organization. She's here to tell us her story. Rosemary, thanks for joining us.

Rosemary Bartel 01:27

Well, I'm glad to be here. Glad to share my story.

Maggie Fox 01:32

Tell us how you first became infected with MRSA.

Rosemary Bartel 01:35

I had a knee replacement in August 2009 and about two weeks later, a couple of days before they were going to take out the surgical staples (from closing skin wounds), I started oozing around the staples. So, when I went in, they had the staples removed, I said to the doctor, I've been having some drainage around the staples. He said, "Oh, what? That's probably irritation from the staples." He took out the staples on Thursday night. By Sunday, I was wrapping my leg with towels, because that's how much drainage there was. So, Monday morning, I called him and said, "You know, I think this isn't going away like you told me it was going to." And he said, "Well, come on in, but I think, you know, it's probably just drainage," and I'm like, "Okay!" So, I went in, and then he looked at it, and he said, "Oh, I think we need to change out the hardware." So they set me up for surgery the next morning, at seven o'clock. They had the hardware changed.

Maggie Fox 02:28

Can you tell us what you mean by hardware?

Rosemary Bartel 02:32

So, they removed the knee replacement and put in new hardware (a new knee replacement). The next morning, after that happened, I was met by a new doctor at my bedside, and he said, "Lady, you're very ill! You have an MRSA infection in your knee. That's why you were having all the drainage, and I give you about a thirty percent chance of surviving this."

Maggie Fox 02:55

That must have been terrifying.

Rosemary Bartel 02:57

Well, I (thought) was like, "You don't know me! I've survived cancer three times. What do you mean by I'm not going to survive this? This is (just) an infection. I'm going to survive an infection." Then, soon after he left my hospital room, I realized I was a lot sicker than I thought I was because I tried to function — open my laptop and send some emails (but I couldn't). I had my dream job. I was the director of education for the Diocese of Green Bay, so I always took work to the hospital with me.

But anyway, that (MRSA infection) led to 58 surgeries, over 200 hospitalizations, 15 times that I was told I had sepsis and septic shock, and sometimes I was in a coma. I've also been intubated several times. I've been flighted from a life flight. I had three amputations. I'm amputated all the way to my waist on my right side. That includes not only the bone but also the tissue.

Maggie Fox 03:53

So, wait a minute, you had a knee replacement. (That) should be standard, and straightforward, and now you don't have a leg?

Rosemary Bartel 04:01

I don't have a leg, I don't have a hip, I don't have most of my pelvic bone. The little strip of pelvic bone that's left — is infected with MRSA. So, I opted to have the tissue around it (removed), because it kept getting sepsis all the time. I kept getting an infection because the bone was still infected. That's why I had opted to have the tissue removed, because if I had the bone removed, then I would have had to undergo reconstructive surgery, and that would have been a much bigger deal than having tissue removed.

Maggie Fox 04:30

So, Rosemary (Rosie), why couldn't they just cure this infection with some antibiotics?

Rosemary Bartel 04:36

Once you have MRSA, you always have MRSA! It's not one of those things that's going to go away. When people don't do good hand hygiene, or they don't do the kind of things that should be done (follow hygiene protocol) when I'm in isolation in the hospital — I always tell nurses, "You can't give me any more MRSA than I already have, but you can take this MRSA to another patient in another bed, or you can take it home to your own family, or you can give it to yourself, but if you're not going to do things the right way, it's not going to hurt me anymore. It's going to hurt other people."

Maggie Fox 05:07

Do you think it was a mistake the hospital made?

Rosemary Bartel 05:11

I'm sure, it was. It was a situation where somehow, I got this MRSA in my knee replacement. Now, this was my fifth joint replacement, and it was not something new to me — I had the other knee replaced by the same doctor at the same hospital. So, it's not one of those situations where you can say, "Well, that's when it happened." It could have happened in surgery — most likely, but it could also have happened post-surgery.

But I know that I did everything by the book (according to the rules) for my preoperative care. They said, from the beginning, "We are having too many MRSA infections we need to do something about (it)." This was in 2009 and within six months they invited me to the table and said "We had too many MRSA infections. Could you help us look at why we're having all these infections? Would you share your story with leadership?"

Maggie Fox 06:06

So, the hospital owned up to its role in this and is trying to fix it, right? And they're still working on this all these years later?

Rosemary Bartel 06:16

Yeah, you pick up other infections as many times, as I've been in the hospital, you know, you end up with things like *Clostridium difficile* (C. diff) and other infections. (One day) I woke up from the coma and I had C. diff on top of MRSA.

Maggie Fox 06:34

You clearly are very familiar with all this terminology and these infections C.diff or C. difficile? It's an infection of the intestines that you get from having too many antibiotics, right?

Rosemary Bartel 06:47

So that, you know, I'd been in a coma for (years). The MRSA had eaten through an artery, and I almost hemorrhaged to death.

When I woke up from the coma, I went to them, complaining about the fact that even though I had a fecal impaction tool, I was still messing with the bed. The diarrhea and stomach pains you get with C. diff are unbelievable. Nobody tells you what C. diff is like. The fact that they gave it (to me) by treating me with a lot of antibiotics to cure sepsis and fight the infection. By doing that, then they caused me to have C. diff.

Maggie Fox 07:21

My goodness, how has this affected your life outside the hospital?

Rosemary Bartel 07:25

Well, it has. I had to give up my job because part of my job was driving. It was traveling to parishes and other places, and the diocese was self-insured, and so soon, I wasn't a good asset in their employment because I was self-insured and not helpful to their insurance. I didn't realize until a couple of years later that they made my life very hard along the way. Then I realized that they were just trying to protect themselves.

Maggie Fox 07:57

Did they kick you off the insurance?

Rosemary Bartel 08:00'

They didn't kick me off the insurance, but they used everything they could to make me retire or resign. When I became an employee, they had me sign a piece of paper that said I could lift 50 pounds. And even though I never had to lift 50 pounds in my job, ever, never would have had to. Suddenly, they're like, "Well, you can't do this anymore. You can't do that. You can't lift 50 pounds, so you can't do what you said you could do." And I'm like, "This is a crazy thing to be saying that I can't do this and so now I can't keep my job" and they made my life miserable. For somebody who worked in the Catholic Church for most of her life — it was a hard struggle to figure out, where my Catholic faith lay and where the politics of the Catholic Church lie.

Maggie Fox 08:49

So, what did you end up doing? What did you do for work? And what did you do for insurance?

Rosemary Bartel 08:54

I ended up having to go on disability. But you know with disability, you don't get insured Medicare until two years later. So first, I used the eighteen months of the Consolidated Omnibus Budget Reconciliation Act (COBRA) — which cost me a lot of money.

Then I had to find another six months of insurance that I went on, first, the state insurance, and then the state insurance got canceled because they no longer were going to provide it to people in the state, and then I had to find private insurance for three months. I will probably be paying hospital bills from that time yet for the rest of my life.

Maggie Fox 09:34

So, you had to mess with all these different ways of paying your medical bills. You are still in debt. And my understanding is you also had to move.

Rosemary Bartel 09:43

Yeah, we lost our home. I only had cash for like one_Basically, those are the kinds of things that just happen. I mean, when people say everybody's like, one major healthcare issue away from bankruptcy, that's very true.

Maggie Fox 09:56

And how's this affected the rest of your family?

Rosemary Bartel 10:00

My husband was my caregiver. And then suddenly, at the beginning of COVID-19 in March 2020, he ended up having a bad backache and went to the doctor, and the doctor blew him off by saying, "Well, you and Rosemary (Rosie) aren't traveling enough. You aren't pushing that wheelchair enough. You need to get out and walk." He tried everything, even a chiropractor. Finally, the chiropractor said, "I'm not helping you. You really need an MRI." On June 26, 2020, they did an MRI, and he got a call that it was COVID, he went to the doctor himself that afternoon, and the doctor said, "I can't believe I have to tell you this, but you have two kinds of bone cancer, and it's secretory to something else. So I got him into an oncologist on the following Tuesday, and he had terminal cancer, and the liver, gallbladder, pancreatic, stomach, and upper gastrointestinal tract, all of it was terminal by July 28 he was gone.

Maggie Fox 10:54

Rosie, I am so very sorry. So, what are you doing now, you're in a wheelchair most of the time.

Rosemary Bartel 11:03

I'm in a wheelchair all the time. I can't get any type of prosthesis because my wound opens too easily.

Maggie Fox 11:10

So who's helping you?

Rosemary Bartel 11:12

Well, I have a son who lives in town, and I have a daughter who lives about half an hour away, and they help me out somewhat, but I'm worried about how to get along and figure it out.

Maggie Fox 11:25

Okay, now let me ask you, this — the hospital admits that you got that infection there, that all of what's happened to you is a follow-up to whatever mistake they made. Why aren't they taking care of you?

Rosemary Bartel 11:40

Because that's not the way it works. I mean, there's only one state that I know of, and that's Massachusetts — they have a law that says that if they admit that they have you got an infection in their hospital, they then care for you for the rest of your life for that infection. But that is the only place where I know everywhere else — you're on your own!

Maggie Fox 12:02

Rosie, what do you want people to know from your experience?

Rosemary Bartel 12:07

I want them to know that hospitals and healthcare facilities really need to hear the patient's stories. Need to hear them, not only by heart but also by mind. Those stories can help them look at why things happen. I want a world without infections. I want a zero-infection world — do no harm, and this is harm.

I've learned a lot along the way about being a more complacent person. I have survived cancer three times. But you know, cancer, if you survive it, it goes away, and this is something that will never go away, even though I had a miscarriage and a premature baby, because I had uterine once I had the hysterectomy, it was gone.

I had cancer in my face. I have a rib and titanium plates for my cheekbone, but once they replaced it, it was better. I often think about why I didn't tell those stories. But I think it's because life went on and things got better.

My life is never going to go back to normal. You know? It's never going to be normal!

Rosie, I am so sorry that you have been through this terrible ordeal and are still going through it. I so appreciate you taking the time to come on the podcast to share your story. Thank you.

Rosemary Bartel 13:21

Well, thank you for having me.

Maggie Fox 13:25

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