



The Unexpected Side Effects Of Chemotherapy

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Guests

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Undergoing chemotherapy is an unpleasant and often disruptive experience that can radically transform a cancer patient's life. From nausea and hair loss, to so-called "chemo-brain" and "metal mouth," the side effects can vary drastically and many are unexpected.

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CELESTE HEADLEE, HOST:

This is TALK OF THE NATION. I'm Celeste Headlee, in Washington. Neal Conan is away. Chemotherapy can be a painful and disruptive experience that can affect almost every aspect of a cancer patient's life. We hear most often about things like nausea and hair loss, of course, but people aren't necessarily prepared to lose, say, the taste of their favorite food, or develop insomnia.

The experience of chemo is as individual and unique as the range of diagnoses. So today, we're wondering: If you're going through or have been through chemo, we want to hear from you. For better or for worse, tell us: What did you not expect? Our number is 800-989-8255. Our email address is talk@npr.org. And you can also join the

conversation. Just go to our website, npr.org, and then click on TALK OF THE NATION.

Later on in the program, remembering Rosa Parks on what would have been her 100th birthday. But first, the experience of chemo. We begin with NPR's Madhulika Sikka. Madhulika is executive editor for NPR News and author of the forthcoming book "A Breast Cancer Alphabet." She joins us now in Studio 3A. First of all, welcome to TALK OF THE NATION.

MADHULIKA SIKKA, BYLINE: Thank you, Celeste.

HEADLEE: So you were diagnosed with cancer two years ago.

SIKKA: I was.

HEADLEE: What were you led to expect from chemo? What did you expect the experience to be like?

SIKKA: Well, they tell you about the things that you sort of think you know about already, the potential for hair loss - which, in the case of the chemo I had, was guaranteed - nausea, which I kind of knew about, too, fatigue, as they call it, which I actually found to be a little too genteel to describe what...

HEADLEE: The word fatigue.

SIKKA: The word fatigue sort of conjures up this image of a Victorian sort of waif who is, you know, prostrate on a chaise lounge...

HEADLEE: On her fainting couch. Right.

SIKKA: Yeah, on a fainting couch. And this was just something much more just deep than a fatigue, that one could rest for a little while and then get up and move around as normal. So those were the things that I was kind of, like, really? I wouldn't use the word fatigue. How about, you know, dog tired in a very visceral way?

HEADLEE: So weary, yeah.

SIKKA: Yeah, and literally it's like some days - not every day, but

some days - there would be days where I was, like, really? I cannot put one foot in front of the other. That's not fatigue. That's something else.

HEADLEE: And another thing that we were very interested to hear about was your surprise over the taste of foods, that you actually - chemo changed the way that you experienced eating.

SIKKA: It did. And, you know, I was familiar with the notion that you would be nauseous during chemo. The thing I discovered is the incredible advancement in the anti-nausea drugs that they give you. So having watched, for example, my late father-in-law 25 years ago go through cancer and see what chemo did to you, I was - I'm very proud to say I was fortunate I did not throw up once because of the gamut of anti-nausea drugs that I had.

So I thought, oh, I'm going to be OK. But what I didn't realize was how much it would just change my relationship to food, both in terms of smell and texture and touch. I kind of likened it to going through pregnancy because, you know, your body is going through this incredible chemical assault when you go through chemo, and it sort of affected my body.

HEADLEE: So give me an example. Was there a particular food that was perhaps a favorite before chemo, and then you couldn't eat it?

SIKKA: Well, there were things like - you know, one of the things that happened is you would get a metallic taste, and that's apparently quite common. And they did warn me that this may happen, and I should, you know, switch to using plastic cutlery when I was eating, which of course makes cutting a piece of meat very difficult - but just so that the metallic taste wouldn't be made worse by using silverware.

And then textures, that was very strange. It's sort of a combination of nausea and touch. So yogurt, for example, I could eat quite easily out of a carton of yogurt. But I literally couldn't stand the texture of it, and just the mere thought of it would make me sick, and of course I would feel sick. And I would be, oh, I've got to eat yogurt because it's got all sorts of good things in it that I need, and

kind of force myself through it.

And as even today, I can't really eat it without something else in it, fruit...

HEADLEE: Even though you're not in chemo.

SIKKA: Even though I'm not - I'm way past chemo. It's a very different experience. So as soon as I sort of realized that, I'm a massive tea drinker, and tea - I'm Indian, I like to drink good tea - I couldn't drink it. And I did not drink tea during my whole chemotherapy.

HEADLEE: Tell me that has come back.

SIKKA: That has come back. And, again, it was exactly like my pregnancy. I did not drink tea during my pregnancy.

HEADLEE: We're speaking with Madhulika Sikka - she's executive editor at NPR News - about some of the things that surprised her, or were unexpected during chemo. And we're asking you the exact same question. For better or for worse, what did you not expect from chemo? You can call us at 800-989-8255, or send us an email to talk@npr.org.

Just like Kathleen in Tennessee writes this: Something quite simple surprised me - and this is similar to what you're talking about, Madhulika. Kathleen writes: I could no longer tolerate chocolate, one of the true indulgences of my life. Also, I was no longer able to concentrate well when reading, another love of my life.

And here's Jonathan in Chattanooga, Tennessee, another Tennessee caller: I had chemotherapy in 1986. What really surprised me was when one of my chemo drugs started to leak or drip on the carpet. All the nurses freaked when I told them. They called in a Hazmat team to come up and clean the spill. It was OK to go in my veins, but don't let it spill on the floor?

(LAUGHTER)

SIKKA: Well, I don't know the exact composition of the chemo. I do know that it's locked away and severely measured, and it is

poisoning your body. I mean, that is what it is doing. Whether it's poisoning the carpet in quite the same way, I'm not sure. But chemotherapy is a pretty strong - it's like using a sledgehammer to hit a nail.

It's an all-body experience to get rid of errant cells. And I'd like to think that in the future, we'll look back on chemotherapy the way we look at leaches, and people say, really? They used, you know, all that just to get at one thing? I think it's exactly the same. It is a total - they have to pump your whole body to get the drugs in that will hopefully kill the errant cells that are there that are giving you cancer.

HEADLEE: I want to ask you something else that many - many people talk about metal mouth, as you were talking about. Another thing a lot of people talk about is chemo-brain. And it sounds like Jerry in Missouri is also calling about that. Jerry, something about chemotherapy that surprised you?

JERRY: Oh, yes. In fact, I identify with all the previous things you were just talking about in the previous minute or so. And my mantra - I don't want to offend anyone in the medical community - but I think essentially in discussion with other cancer patients that the - I think the philosophy is we really don't know what this stuff will do to you when we give it to you, but we know what's going to happen if we don't.

So let's err, you know - everything from neuropathy and joint pain, which has kind of stayed on semi-permanently. But the effects of chemo-brain, I've - for the first time in my life, I've had to make lists of things. I really identified with your other comment you read about - I've been a reader all of my life, and I will find myself having to page back when a character's name comes up because I've kind of forgotten who they were.

HEADLEE: Oh, interesting.

JERRY: And it's like short-term. I don't think my long-term memory is affected - of course, I really would have no way to know. But in the short term, cognitive function, I definitely have noticed a difference.

SIKKA: And I think that you raised two things close to my heart: chemo-brain and joint pain, which is sort of an after-effect, which I still suffer from, which I think is partly due to the chemo and partly to the drugs that I'm on now, and in the grand scheme of things seems not as important as, you know, what oncology is focused on, which is your cancer. But it affects your quality of life.

And chemo-brain, like you and the other emailer, I'm a big reader. I thought, oh, I'm going to be home resting during chemo. I have stacks of books, things I'll be doing. And if I could get through 500 words without taking a break, I considered myself very lucky.

HEADLEE: Wow.

SIKKA: And it's interesting that chemo-brain affects you in that way, and I completely hear you on the short-term memory thing, which has gotten better. But I'm pleased to say that it's not in our imagination. You know, there was a report recently that actually validated the notion of chemo-brain. Of course, I didn't need to have someone else...

HEADLEE: A study to tell me that.

JERRY: When it comes to joint pain, I mean, I'm in my middle-50s, and I think reasonably in good shape. But the first few steps out of a chair after sitting down for a while, I look like George Burns trying to walk, you know, until it kind of works its way out.

HEADLEE: And Madhulika is signaling. You can't - this is radio, so you can't see her pointing to herself and saying me, too. Thank you very much, Jerry, in O'Fallon, Missouri.

JERRY: Thank you.

HEADLEE: Let me read this email, here. This is from Rosemary in New Jersey, and Rosemary writes this: I wasn't expecting to lose my eyelashes, or most of them, when I was going through chemo. You brace yourself for certain things - loss of energy, loss of appetite, loss of hair on your head. You have no idea, though, how much junk eyelashes keep out of your eyes until they're gone. Lucky for me they grew back, though never as lush.

The other surprise was gaining weight on chemo. I was grateful to be spared the nausea so many chemo patients suffer and to be able to reassure loved ones I was far, far from wasting away, in spite of stage two ovarian cancer. Happy to say that was in 1998, and I've been cancer-free ever since. So congratulations, Rosemary.

So what about this? I mean, you say losing your hair. I think people forget that that includes not just the hair on your head.

SIKKA: It includes your hair in all sorts of other parts of your body. I mean, I - you know, your arms, your eyebrows. I, for some reason, really struggled with the eyebrows, maybe because I wasn't so good at painting them on as some people are. And it would - your face is bloated because you have - you're on steroids during the chemo. And, you know, on those really dark nights when you look in the mirror and you see this sort of billiard-ball face with no eyebrows, it's tough.

It's not vain. It's just the reality of your treatment staring at you in the face. And it's a little dispiriting sometimes.

HEADLEE: Yeah, you look - you don't recognize the person in the mirror, I'd imagine. Katherine in Tucson, Arizona, writes this: My sense of touch was diminished. I could no longer feel anything in my purse. I'd have to look inside it to find my car keys. Madhulika Sikka, did you have any of that?

SIKKA: I had a lot of tingling in my fingers and toes. So holding things would sometimes be really difficult. My eyesight went a little south, as well, but, you know, I'm middle-aged. So it was a whole combination of things. But when I raised this issue, the doctors would talk about oh, yeah. That's the neurotoxicity - as if oh, yeah, you know, that's like banging your thumb, or something like that.

But, you know, I thought the things I like to do, I like to knit. It was hard to hold knitting needles, because your joints hurt. But, yeah. You just don't think that it's going to reach the extremes of your body the way it does.

HEADLEE: So we're wondering, if you've gone through

chemotherapy, or you're in treatment now, tell us: What surprised you about the ways it affected your life? 800-989-8255. The email address is talk@npr.org. We'll have more with NPR's Madhulika Sikka after a short break. I'm Celeste Headlee. This is TALK OF THE NATION, from NPR News.

(SOUNDBITE OF MUSIC)

HEADLEE: This is TALK OF THE NATION, from NPR News. I'm Celeste Headlee. Whether a cancer patient receives therapy at home, in a hospital or at the doctor's office, chemotherapy can come along with a whole host of disruptions. You have your work life, personal life, social life. They all take new shapes as a patient responds to the demands of the regimen and the - hence, the disease.

So if you have been through or are going through chemo, we want to hear your story. For better or for worse, what was unexpected? Our number is 800-989-8255. The email address is talk@npr.org. Or join the conversation at npr.org, and then click on TALK OF THE NATION.

With us, Madhulika Sikka, executive editor for NPR News and author of the forthcoming book "A Breast Cancer Alphabet." And joining us now from our New York bureau is Suleika Jaouad. Suleika has been chronicling her experience with leukemia for the New York Times. Her column "Life, Interrupted" runs on the New York Times Well blog. And we're so glad to have her back on the show. Welcome, Suleika.

SULEIKA JAOUAD: Thanks. I'm happy to be here.

HEADLEE: You were diagnosed at the very young age of 22. You probably hadn't spent a lot of time at that point thinking about chemo or imagining what it might be like to go through it. What did you expect when you found out you were going to have to have chemotherapy?

JAOUAD: I think leukemia, weirdly, is a popular cancer for people to have in movies. So, you know, I was vaguely familiar with what leukemia is, and I understood that I was going to lose my hair. But

beyond that, I never really experienced cancer, you know, first or secondhand, for that matter. None of my friends had ever had cancer.

And I think I was completely unprepared for the emotional, lived experience of cancer and for the social awkwardness that comes with having to tell people that you have cancer, and you're 22 years old. It's something that doesn't make sense. Youth and health are supposed to go hand-in-hand.

HEADLEE: One of the things that you're writing about, I understand your next piece is actually about something that people - I guess doctors - rarely talk about when someone's heading into chemo, and that's sexual health. First of all, why do you think people don't talk about this very much, and what was it that you wished you'd known?

JAOUAD: I think that cancer is the emergency. So it's not that health care providers don't care about your sexual health, but it's something that's sort of pushed to the wayside. And people assume that someone is going to get to it at some point or another.

What was very shocking for me, actually, was, following my diagnosis, I typed acute myeloid leukemia into Google, and one of the long-term side effects of the chemotherapy treatment I was scheduled to undergo was infertility. And that really shocked me. I didn't know that high doses of chemotherapy or radiation have the possibility of making you infertile.

So that was a big conversation that I had with my oncologist, but maybe I didn't quite understand the implications of infertility. So recently, what I've been going through is early menopause, which is very difficult, I think, for...

HEADLEE: Early menopause at the age of - how old are you now?

JAOUAD: Twenty-four. It's difficult for a woman of any age to kind of wrap her head around, but that was an issue that no one talked to me about. And I think, you know, there are a lot of sexual side effects of chemotherapy, ranging from pain during intercourse to inability to orgasm to early menopause. And, you know, these are

issues that I think are extremely important, both just in terms of understanding the changes that are happening in your, body but also, you know, with regards to your relationships or to partners.

And if you can't have that conversation with your doctors, then it's very difficult to have that conversation on your own, without the vocabulary or the information that you might need to be educated about what's happening.

HEADLEE: Which kind of leads to this whole idea that while chemotherapy's going on, life doesn't stop, right? And that's - I guess - it sounds like that's the point that Charlotte in Virginia wants to make. Charlotte, what surprised you about chemotherapy?

CHARLOTTE: What surprised me the most was the sense of trying to balance, that one is still a mother with responsibilities of picking up - one day I forgot to pick up my children at school, and the very nice secretary at Percy(ph) Elementary called and said: Your kids are in the office. But it was the sense of not being alienated from oneself, that you are still yourself in the role, but it's one degree of separation.

HEADLEE: That's interesting. That's Charlotte, calling from Virginia. Madhulika, do you have that kind of same experience?

SIKKA: I think the thing that struck me most was you discover very quickly that the world doesn't stop for you to get off. And you - part of you thinks it should, because you're going through this terrible thing. But, you know, your roof still leaks and bills still need to get paid, and you still have a husband, in my case, who want a little bit of your time, or - you know, it impacts the family dynamic in a very different way.

And, you know, part of you thinks that, oh, I've got the best excuse in the world to just give up on everything. But then you feel like you've let it win by giving up on everything. So it's a sort of battle every day to sort of figure out the right balance.

HEADLEE: And let's go here to Laurie, calling from Tucson, Arizona. Laurie, what surprised you? What were you not expecting after chemo?

LAURIE: I think that the weight gain was really very surprising to me. I really thought that I would actually - as ridiculous as this sounds - you know, I was going to lose weight. And because I wasn't going to be able to eat for a while, and I thought, OK, not a great way to lose weight, but on the other hand, if I can get a start on losing weight, and then I'll keep it up afterwards.

It didn't work that way at all for me, not at all. I ended up gaining weight while I was on chemotherapy. I gained more weight once I started eating after I was able to taste again. And I have not been able to reduce my weight. That was completely unexpected and never discussed.

HEADLEE: That's Laurie calling from Tucson, Arizona. And I understand - we also have with us on the phone, from New York, from the New York bureau, is Suleika Jaouad, who's chronicling her journey with leukemia for the New York Times. Suleika, you actually saw a change in your relationship to food, especially your mom's cooking, right?

JAOUAD: That's right. It was interesting, because in the beginning, I had no appetite whatsoever. I was in the hospital for several weeks at a time. And my mom would say, you know, like, let me cook your favorite foods. So she would bring me my favorite foods, and I could barely get through them. But what actually ended up happening is that after a few months, I started associating my favorite foods with nausea.

So now I've started - I'm still in chemotherapy. So I have a different approach. I actually save my favorite foods for when I'm not in treatment, so that I don't have that trigger response of nausea.

HEADLEE: So you don't ruin it.

JAOUAD: Exactly.

HEADLEE: And Madhulika, you're nodding your head, that this makes sense to you.

SIKKA: Yeah, absolutely, because you don't want to ruin the good - you know, I think food is as much about pleasure as it is about sustenance. And I like to cook, and it would be terrible if I, you

know, had to completely rearrange my relationship with food permanently. So I think the trick that worked for me - and I think for anyone going through chemo - worth trying is find what you like to eat, and eat it and take the other stuff off the table until you're ready to face it again.

You know, as in the previous emailer, you know, if chocolate is your thing, and it doesn't work for you, stop eating chocolate so that you can enjoy it at some point in the future.

HEADLEE: And there's something - somebody emailed about this, as well. Stan writes: When my mother was having chemo, she lost her sense of taste for almost all foods. To compensate, she wanted salsa on everything. I suspect it wasn't that she could taste the salsa, but it gave her mouth a heat sensation, that at least was something to make the food appealing.

She never before or never after has wanted salsa. It was funny. Now she looks back at it and laughs. So, you know, there you go, Suleika. Some day you'll look back at it and laugh, right?

JAOUAD: That's right.

(LAUGHTER)

HEADLEE: But what are the other ways, Suleika? I mean, the question we're asking our listeners is what surprised them, what was unexpected. So besides, you know, sexual health and then your relationship with food, was there anything else that you weren't quite prepared for?

JAOUAD: I was surprised by - I guess when I first got diagnosed, you know, everyone was talking about what type of chemo do you do, what type of medications, and the focus wasn't so much on emotional wellness. And I think I was surprised by how incredibly isolated I felt as a young person with cancer.

And, you know, I have these questions where I log on to my Facebook, and it would be my old profile picture with long, you know, waist-length hair. And I think to myself, like, do I come out of the cancer closet on Facebook? Do I update my profile to reflect where I am at now in my life?

And eventually the answer to that question for me was yes because this has been, you know, a two-year battle that's ongoing, that there are all these social questions of, you know, how do I tell someone I have cancer? What do I do if they don't know what to say?

And I've slowly, over time, learned to take initiative, especially when it comes to having a conversation with friends about cancer and saying, you know, and learning that it's up to me to set the tone because a lot of people, if they walk into a hospital room and see you bald for the first time, aren't going to know what to say about that. So, for me, I would say, oh, how weird do I look with bald hair, or something like that...

HEADLEE: Right.

JAOUAD: ...you know, just to kind of get it out there and to put it out there.

HEADLEE: You're hoping it - easier for them, yeah.

JAOUAD: Right. And to, you know, and to let them know that it was OK to talk about these things. And I think the other thing that really helped me was finding a community of people who are going through similar ordeals even if they do not have the same cancer as me.

And I was never much of a social media user before I got sick. But what I found to be kind of incredible is this vibrant community of cancer patients who tweet, who blog and who write on Facebook, and it's really kind of an incredible thing. I think for a lot of people, you know, social media can feel like it eats up too much of your time or it can be a waste of time. But when you're isolated in a hospital room or you're bedridden...

SIKKA: Yeah.

JAOUAD: ...the Internet and social media can actually be your only way of connecting to other people in a sense.

HEADLEE: This is something that is also in the mind of Max, another caller from Martha's Vineyard. And, Max, emotional health is also something, I guess, that you weren't prepared for in chemo?

MAX: I was not prepared to feel so isolated. I was not prepared to be so afraid to, like the - like your guest was saying, so afraid to talk about what was going on. I didn't realize that being out of work - and I was in my early 30s at the time - I didn't realize that being out of work and out of the social sphere was going to make me so depressed.

And I didn't have a family at the time. I was dating someone. I didn't know how to talk to him about it. And I became extremely isolated. Social media was not so prevalent at the time, so I didn't have that avenue. And I ended up really desperately needing antidepressant medication to get through my treatment.

HEADLEE: That's Max. Thank you so much, Max, calling from Martha's Vineyard. We're talking about things in chemotherapy - and they can be bad or good - that surprised you. You're listening to TALK OF THE NATION from NPR News.

Let me bring this back to you, to Madhulika Sikka, because we're talking about things that, like I said, surprised people about chemotherapy. Is there a way that a doctor or a hospital can prepare you for these things?

SIKKA: I think, frankly, they do the best that they can, given the fact that most likely your doctor hasn't been through it. So if you - like they're giving you the benefit of secondhand reporting. You know, some hospitals have groups, support groups that you can get together with other people. I, unfortunately or fortunately, I did not need to use one of those because, sadly, I'm of an age where it seemed to me that breast cancer was sort of epidemic, and I knew so many people directly or someone who knew someone that I kind of could build my own support network.

And what I did find was that once you're on the other side, the women who I had looked at who'd gone through it - and I saw it from the outside - they were so brave. They were so strong. But once you were in the club with them, they shared the things with you that you might not have known as an outsider. So you suddenly felt like, oh, I feel like this. And I would call up someone or email someone, and they're like, yeah, that's exactly what it's like. Or they would warn me about things that I would go through.

I think there's no better substitute than talking to someone who has been in a like situation with you and the extent to which the doctors and the medical community can help put you in touch with people. I think that that's probably of a lot more benefit than the doctors. You know, the doctors have to be generalists because they are dealing with lots of different types of cancer, lots of different types of chemo, and all of them are a little bit different.

HEADLEE: So give us your status update at this point, Madhulika. Before we go, where does the - I mean, obviously you're writing a book. Things seem to be going pretty well. Where do you stand now with cancer?

SIKKA: Well, I don't like to use the word survivor, and no one has ever used the word remission. One thing I did learn about cancer is it's all about odds, and you have to learn what somebody I know calls medical math, and you have to figure out your odds. And what the doctors are doing is helping you reduce the odds, once they have treated you, of it coming back. So I'm on medication right now which I stay on for five years after my chemotherapy.

HEADLEE: Five years.

SIKKA: And hopefully, that's going to reduce the odds of it coming back. You just have to be vigilant and it sort of struck from nowhere, in my mind, not a history in my family. Who knows it may come back, but if it comes back, it's not because we haven't fought hard to try and keep it away. So I'm working. I have hair. I eat well. So things are looking up for me.

HEADLEE: That's Madhulika Sikka and unto you Suleika Jaouad, this is obviously a journey that you're still on. What's your status update?

JAOUAD: It's just a strange thing because I'm actually cancer-free right now but it's just really exciting. But because of a high (unintelligible) of relapse, I do a week of chemotherapy every month that I've - that I'll do for a total of a year. It's just, you know, I've been sick - I feel like, for so long, maybe (unintelligible) It's nothing compared to a lot of people.

HEADLEE: Yeah.

JAOUAD: But it's been exciting for me to recently try and take charge of my body and my health and my nutrition. So one thing I'm doing is...

HEADLEE: Well, we have to end it there, unfortunately. Best wishes to Suleika Jaouad who writes the Life, Interrupted column for New York Times Well Blog. She joins today from our New York bureau. And Madhulika Sikka is executive editor for NPR News, author of the forthcoming book, "A Breast Cancer Alphabet." I'm Celeste Headlee. It's TALK OF THE NATION from NPR News.

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