

Csilla: It's very liberating. I was really surprised. Because I did not expect to like myself bald. And then my son, he said, "Mom, you look tough." And I thought, 'Okay, I like that.' Because for sure I did not want to seem scared to him. Because I did not want to scare him. So I thought, 'Okay, I'm not feeling that tough, but I like the tough look. And I will kind of live up to that, and find that inner strength somehow.'

Hi, I'm Csilla. I'm a mother, a teacher, a boxer, an artist, and a free spirit. And right now, I'm in my second year cancer free.

Caitlin Kiernan: Cancer is not pretty. The side effects can impact not only how you feel, but also how you see yourself. Whether you want help learning how to create eyebrows from scratch, need to know how to treat a radiation burn, or are just looking for wig shopping tips, you've come to the right place. Welcome to the Feel More Like You podcast, presented by Walgreens and *Pretty Sick, The Beauty Guide for Women with Cancer*. I'm the book's author, and your host, Caitlin Kiernan. In each episode, we'll break down the important information to help you look and feel more like you. In this episode:

Female: Just a big clump of it from the crown of my head came out in my hand, in the shower, and I kind of just looked at it, and that's when I kind of lost my mind.

Female: You kind of feel like you're channeling Britney Spears.

Female: But I could not get over how freeing it was.

Female: It's extremely popular, and it is kind of the way now. It's really in fashion to wear wigs and be able to change your look and switch up your hair.

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On today's episode, we're going to talk about hair loss on your head. We want to deep dive into the significance of our hair, and how to prep for when it falls out. I'm joined today by Walgreens pharmacist Emily Shafer, beauty consultant Laura Catron, and health editor Emily Ornberg. Hey, gals.

All: Hey, hello. Hi.

Caitlin: So I think hair loss—I mean, obviously, it's a big thing, but it is—it's really driven home by the fact that it is the number one question that women ask their doctors after hearing their diagnosis. I mean, to me, it really just drives home

how important our hair is. Because it informs our identity. It leads information to what our ethnicity is and our style, and, just everything. Emily Shafer, tell us what's happening. Why do we lose our hair during chemotherapy?

Emily S: By definition, chemotherapy is designed to stop rapidly dividing cells. This not only includes your cancer cells, but also other cells like your skin and with your hair, specifically, it's going to fall out. It could stop growing and fall out. Most patients will lose their hair as early as about 7–14 days when starting treatment, or those hair changes will come out. And that hair loss will continue through your treatment, and even for a few weeks after you stop.

Other treatments, though, you may also experience a hair thinning, or partial hair loss. Hormone medications such as Tamoxifen can impact hair. Radiation can also affect your hair. If you have radiation, in particular places in your body. But whether your hair thins or you become completely bald will depend on your type of treatment. So ask your doctor or your pharmacist about what your side effects will be before you even start that treatment.

Caitlin: I was shocked at how fast my hair started to fall out. Like it does, it happens real quick. But I only—because I was on CMF, which is a certain chemotherapy protocol, I didn't lose all my hair. I lost a third of my hair. And that can be just as stressful, because you're like trying to keep all the hair on your head to stay in your head and it's not—you know, it's like coming out. Laura, my question to you is, is there anything you can do from a beauty consultant standpoint to help that?

Laura: So I think kind of what you all were just talking about, there's certain things that you can do that can really help to minimize it. I mean, I'm not going to say it will keep it from falling out, but it will help it not fall out as fast. So, like, very gentle shampoos. Always, always with a gentle shampoo. Even the way you brush your hair, holding on to the scalp, and just starting from the ends and then working your way up, so like the tangles aren't going all the way through, and then brushing your hair before you take a shower, so you're not just trying to work through wet tangles.

And even things like wide-toothed combs, or letting your hair air dry, and keeping that heat damage off of it.

Caitlin: And we're not saying that those things are going to prevent your hair from falling out. Your hair—if it's going to fall out, it's going to fall out.

Emily S: It's going to fall out, yeah.

Caitlin: But these gentle approaches to managing and handling your hair will certainly be beneficial, because they're not going to be putting a strain on your hair and causing more of it to fall out.

Laura: Absolutely.

Caitlin: Emily Ornberg—hello, lady friend. I want to know what you heard from survivors. What did they say about their hair loss?

Emily O: So, just like there's different types of cancer, different types of treatment, different side effects, the way that hair loss affects patients emotionally is vastly different. From all across the board. Of course, a majority of them were devastated by it because it's so much part of our identity, but some women, once they got through that experience, said, "You know, this is the most freeing thing. I never felt so bold and brave!" And they just felt the power of it. So you should allow those emotions to feel. Feel the way that it feels. And just don't bottle them up. This is way more than just hair. This is a huge part of you, and share with a friend, talk to a counselor—just know that hair is more than hair.

Caitlin: Yeah. No, I agree with that. I also think there are a lot of things you can do. There are wigs, there are scarves, there are really cute beanies that are so on-trend. You can put Swarovski crystals on your entire head, you can henna your head—there are options for getting through it stylishly. And I think it's just like—try to have a positive attitude about it. Try to make the best of it. Because it just sucks. But it's—you know, there are options.

Before we close, I want to hear your tip—your takeaway tip. Laura, I'm going to throw it to you. What's your tip?

Laura: My tip for if you lose your hair is SPF. Make sure that you are covering—

Caitlin: —Good one—

Laura: —Everything.

Caitlin: Yeah.

Laura: Because—I can't imagine covering everything and then completely forgetting about a spot that you've never put on before, and then getting a sunburn.

Caitlin: And the chemotherapy does make you more susceptible to sunburn.

Laura: Absolutely.

Caitlin: So that's just a great tip, because who would think about—if you're not used to putting sunblock on your head, you're going to forget it. But that's a great tip. And follow it down—on your ears, on your neck. Yep, excellent. Emily Shafer, tell us your tip.

Emily S: I love your SPF, so, yes, very pro-SPF in the health care world.

Caitlin: So pharmacist of you to love that tip!

Emily S: I think that something that maybe people don't realize—if you're going to go and get a wig, there's many different kinds of wigs. Insurance often will pay for

that. So if you get a prescription that says that it's a cranial prosthetic, or there's certain phrases that certain insurance companies will find credible, the right CPT codes, the right way to bill it, you can get those paid for by your insurance. And your pharmacist, and your pharmacy, especially your specialty pharmacy, are great resources to help you find out what you need with your insurance in order to get that paid for.

Caitlin: And also the Cancer Support Community—they have so many resources to help you navigate your health insurance. Because there are pockets and little ways to try and get your wig coverage. Because my insurance was going to offer me 200 dollars. I'm like, I'm not really sure what that's going to cover, but, you know—

Emily S: Well, and I mean—utilize your resources to find out what the right questions are to ask. Because if you don't even know what you don't know, that is so overwhelming. So put that on these other people who have so much experience with that so that you can use your insurance that you're paying for and you're working hard for.

Caitlin: Absolutely. Great information, ladies.

Let's hear from our survivor sisters. What did your hair mean to you, and how did you cope with hair loss?

Christine: Hi, my name is Christine. I'm a high school science teacher and I have ovarian cancer.

My hair started to break off. And then, when I was in the shower, I was washing my hair, and it was coming out in clumps. And I was like, okay, so we need to go ahead and shave this.

So I called two of my friends, and I said, 'Come on over and shave my head.' And so we kind of had a lot of fun with it. Like the first thing we did was like took the clippers and went straight down the middle of my head so I looked like an idiot. I mean, it was fun. I got emotional, because it is kind of shocking. I mean, the last time I was bald I was a baby.

There are very few things that you do have control over when you have cancer. And so when you can find something that you can jump out ahead of, or that you can take control of, is very empowering. Because it's like, okay. I'm bald because I shaved my head. My hair's not growing back because I'm on chemo, but I got in front of it. And it felt really good to take control of that.

Emily: Hi, I'm Emily. And I'm a math teacher, a mother, a wife, a sister, and a daughter, and I have breast cancer.

I had long hair. I did not want my long hair falling out. I think that would have been devastating. So I had a shorter haircut which I did not really like, and then I dyed it pink. So when it fell out, it wasn't so upsetting. To be in control of the hair. That's all I really wanted, is control of the situation.

Deanna: Hi, my name is Deanna. I am a beauty writer in New York, and I've had cancer three times.

At this point, I was trying not to touch it at all, or get it wet, and even so, like just a big clump of it from the crown of my head came out in my hand in the shower. And I kind of just looked at it. And that's when I kind of lost my mind, and it—it really hit me. That day, I got my wig, and I got used to having no hair. Even in the shower, I kept shampooing my scalp, partly because I was bored. I even conditioned my scalp, because it was such a big piece of my routine, and that sense of familiarity I had in my mornings, that—I didn't want to lose it. And it gave me a lot of comfort. Sad comfort, but it was still comfort.

Stephanie: Hi, my name is Stephanie, and I'm a realtor, I'm a certified life coach, and I just happen to be a breast cancer survivor.

The bar's just pretty high for women. We can't do this, we've got to look this way, these doggone beauty magazines put this stuff out there. There's all this pressure on us. There's pressure on us to look good. I mean, here we live in a culture where men are purposely shaving their heads because it's cool, it's hip, they look good. And God forbid a woman loses her hair.

I was 40 when I did it. And it was so empowering. And the biggest lesson I learned was—it's just hair. It's just hair, and it'll grow back. And then I couldn't identify myself by my hair. But I could not get over how freeing it was. And just to—oh my God to have those moments when you feel the breeze go through it. There's just some sort of connection with the universe, with nature. For me, there was just that sense of being connected and being at one.

And you want to hear the irony? The irony, is, I never got so many doggone compliments as when I shaved my head. It's amazing. It's amazing.

Brianna: Hi. I'm Brianna. I'm a writer and I survived Hodgkin's lymphoma. Losing my hair gave me an opportunity to have a little bit more fun. Before and after. Being blonde first, and then bald, and then purple wig all the time. So taking that opportunity to just like, have fun.

Caitlin: Hair. It really means so much to our identities. Without it, it can feel like an instant sign we're sick. Being a public person in the middle of a cancer diagnosis, comes with its own unique set of challenges. Imagine losing your hair on TV. Just ask Joan Lunden.

Emily O: For nearly two decades, Joan Lunden hosted *Good Morning America*, making her the longest-running female host on early morning television. But in June of 2014, Joan was diagnosed with triple negative breast cancer, and faced her cancer journey in the public eye. Caitlin sat down with Joan to hear her story.

Caitlin: Tell us a little bit about when you were diagnosed and the type of cancer you were diagnosed with.

Joan: Well, I'm happy to say that I just had my five year anniversary this week.

Caitlin: Woo-hoo! Yes!

Joan: Woo-hoo!

Caitlin: Yes. That means so much.

Joan: June 5, 2014. I had a 3D mammogram that day, and it was clean. And then I went across the hall, and I had an ultrasound, and I heard those words none of us ever want to hear. "You have cancer." I had stage 2 triple negative breast cancer. You know, I really actually feel like I almost lucked out, which is kind of a funny thing to say, since I was—had no hair for a year, but I didn't have to have a mastectomy. And I have girlfriends now who I am going through it with, and, I mean, they have just had so many surgeries, having this, mastectomy. I only had to have a lumpectomy.

Caitlin: You mentioned that you were a year without your hair, which we say it so cavalier, and it's really just such a crazy experience. After you were diagnosed, and you learned that you were going to lose your hair, how did you begin planning for that? Especially, you know, you're a public person. And that—how did that shape going into that part of this experience?

Joan: Yeah. It wasn't just my vanity, it was my career. It really was incredibly scary. Like, I had lots and lots of appearances scheduled. So fortunately my oncologist sent me directly to the wig store, and said, "I want you to buy a wig right away. Before you lose your hair." And fortunately, when I went to the wig store, I had a great guy who was the consultant, and he said, "All right. You haven't shaved your head yet," because I hadn't done that yet. He said, "We're going to cut this wig. We're going to try and make it look just like your hair."

But he said, "I want you to put the wig on. Shove your hair all up underneath." And he gave me a little net. And he put the wig on me. He said, "Take this baby out for a spin. Wear it a couple of days." So I called a girlfriend. She met me for lunch. She didn't say anything. We went to have a mani-pedi, and as we sat there, I said, "Do you realize I have a wig on?" And she said, "You know what? It did—your hair did seem a little different, but I just thought it was a different style." This was one of my best, best friends! And that said to me, okay. You're going to be okay.

I found great value in putting that wig on, and going out before I was a bald person. Before I felt so different. I was still me, I was still myself. So I really think if it's at all possible, go out and—it might seem like you're putting vanity right up there in those first couple days of those important appointments when you're trying to figure out which chemo regimen to take—but how you look for the coming months as you walk through your life, is also really, really important to your psyche and your ability to hang on to hope and to try to feel normal as you're going through—at a time in your life when you're anything but normal.

Caitlin: Right. I agree. Tell me about that day when you shaved your head. Tell me about—

Joan: Oh, I can't even begin. It's almost like you're in the twilight zone. They put that shaver up next to your head, next to your ear, and you feel that vibration, you hear that electric razor. It was weird. You kind of feel like you're channeling Britney Spears. But it's empowering. *People Magazine* had also called and asked me if I would be on the cover, and if I would be bald. And I said, "I don't know if I can do that." But they came to my house. We shot it three ways. We shot it with my wig, and with my—a little, like an Hermes scarf that they put around my head.

And then they cleared the room. And the photographer and I, there alone together, we shot me bald. And when I looked at the pictures, I just said, "If this can give hope to anybody else going through this, then that's going to be meaningful." So I went with it. You really feel like—it's kind of like a warrior move. And I did it. The cancer didn't do it.

Caitlin: I want to back up and talk about the difference between real hair wigs and synthetic wigs. I feel like a lot of women feel the pressure to try to get a real hair wig. But a real hair wig is expensive. And as you told me about your real hair wig, they're also a lot of maintenance. Tell me about that.

Joan: So I felt that I had to get a real hair wig, but that's because I'm on television all the time. And I don't know whether I would have done that and spent that kind of money, although my insurance did pay for that wig. But I also bought a couple of inexpensive, fun little synthetic wigs. I always say, look, you can say to your husband, "I'm going to come in as someone different every night."

Caitlin: How fun!

Joan: How fun is that? I mean, if—you've got to find ways to have fun with this, but quite honestly, most of the time, I wore the synthetic wigs. Because that real hair wig had to be washed and blown dry. And you have to get that head—I mean it's a whole—it's a really—

Caitlin: —Because it's like a real hair—

Joan: —It's a lot of work—

Caitlin: —Head of hair. You've got to blow dry it and style it.

Joan: And it's hard to do on your own head. I mean, you can try to like—because you don't have anything to pin it to, because you don't have any of your own hair.

Caitlin: It's like sliding all over the place.

Joan: It's—it's a lot of work. And today, in this world, they have the cutest synthetic wigs, they look so real. You just have to make sure you get one of those kinds

that has like that mesh front so that you don't see where the wig starts. Like, in the old days, the wigs, you could tell where they started—

Caitlin: —They're so good—

Joan: —But you really can't these days. So I wore my synthetic wig 98 percent of the time. And they—they didn't look exactly like my real hair, but they were fun. I actually had—I actually had some fun with those wigs. I still have them.

Caitlin: That was some great information from Joan. Here's her quick recap.

Joan: Number one, let them see what you look like before the hair falls out. It's really important. Number two, you lose your hair much faster than you think, like in about seven or 14 days. When your hair begins to grow back, you might want to look for some travel size or mini tools to style your hairs. Because it comes back really, really short and curly sometimes. I had straight hair. It came back curly. Those little mini brushes and flat irons were really great at grabbing those super short strands of hair.

When your hair begins to grow back, don't rush to color it. The minute my hair grew back in, I wanted it blonde and it was kind of looking ash brown. My colorist, though, didn't know, as I didn't know, that if you color your hair before all the chemotherapy chemicals are out of your system, your hair can turn, in my case, a bright shade of orange. So don't make the same mistake. Be patient. Having gorgeous hair color is worth the wait.

Caitlin: The Kardashians have made wearing wigs a huge trend. But for those of us who have to wear them, it can feel overwhelming. All the styles and varying price points can be dizzying decisions for those in a race against time. We're going to try to help you understand all the wig options, and dare I say, make it a little fun. And who better to hear from than Beyoncé's hairstylist and wig maker, Kim Kimble.

Emily O: Whether it's floor-length braids for a Nikki Minaj video, three and a half pounds of curls for Oprah's *O Magazine* cover, fantastical pieces for *A Wrinkle in Time*, or dozens of iconic Beyoncé performance looks, Kim has created hundreds of unforgettable wigs. As wigs have become more popular, they're also more realistic, stylish, and affordable. I spoke with Kim to get her advice on how to make a 50 dollar wig red-carpet ready.

Kim Kimble: It's extremely popular. And it is kind of the way, now. I don't have to say most of the entertainment industry utilizes wigs. It's a fashion thing now, it's really in fashion to wear wigs and be able to change your look, and switch up your hair. But also, too, some people use it as protective style. You know, protecting their own hair from damage of the day-to-day wear and tear, and changing up the looks. People are—you know—because they see some of their favorite celebrities wear wigs, that they have also picked up the love of wigs.



Emily O: When you're shopping for a realistic wig, what are some qualities you should look for?

Kim: Textures are very important in making wigs look natural. Getting it with a little bit of texture that can really mimic what your hair does. If you are like a multi-cultural, African-American descent, there's a lot more textures that mimic our hair now. Because originally, when wigs came out, they were more for just straight. Getting a wig where—even if you're Caucasian—their hair is wavy, even. Getting it with a little bit of texture. We rarely just sell bone straight wigs. Making sure it has a great cut. Because a lot of times, the hair comes, just long. Most people have some kind of cut, or layers, or even some split ends.

Emily O: And what else can someone do at home to make their wigs look a little more natural?

Kim: Well, you could take a little—like a razor, like an eyebrow razor, and kind of razor—you create baby hair. I know baby hair—but you have to be careful, because some people will overdo it with the baby hair. Color techniques are great. You definitely can use any color, retouch up, enhancements, I like eye shadow. Makeup palettes to fill in roots and enhance parts. To make them stand out more. To look more real.

Emily O: What would you say—what does our hair mean to us?

Kim: Oh, gosh. Hair is—sometimes if our hair isn't right, it could change our whole demeanor, and our whole confidence level. And I know how my clients—I see how they—when they perform, how they change. Their hair is together, and they can take on a whole new character. A whole persona.

Emily O: Whether you're wearing wigs to have fun, or just want to look more natural, wigs can help keep your cancer journey a little more private. Here is survivor Virginia.

Virginia: I was the manager of a restaurant on the Upper East Side of New York. And sort of the face of the restaurant. And I just didn't want to have to share what was going on with everybody who walked in the door. So I got a wig. A good wig. I didn't love wearing the wigs, but it looked like my hair, and most people that I didn't know well never knew that it wasn't mine. I had it cut the same way that my hair had been, so I didn't experience the hair loss as such a terrible thing as I thought I might.

Get a good wig. Spend the money. Unless you go the way my friend went, who bought wigs in every color of the rainbow and wore a different one every day.

Emily O: Brianna used wigs as a way to express her many styles.

Brianna: It's fun to be able to try on a lot of different hair styles on yourself. I have a couple wigs still that I got during that time. It was—one was kind of like how my hair looks now, just long and brown, for—my friend got married that summer,

and I was in her wedding, and I didn't want to look sick in all the wedding photos. But that's advice I would give to people is—don't be afraid to have people take pictures of you and remember those times, because you're still yourself. But the wig I wore most often was bright purple. So taking that opportunity to just have fun.

Emily O: And Csilla found her wigs to be a source of positivity and a way to connect with others.

Csilla: I really don't want to just pretend that nothing's happening to me. I went to the wig shop, and I was looking to find something that would fit me. Everything seemed so boring to me. And I thought, okay, we need color. And so I thought of the wig as also a way to raise my positive mindset. But also play. Let's play a little. I thought, 'Okay, I'm going to lose my hair. Let's do something different. Something I always wanted to do, but never really had the guts to do. Let's wear some pink hair or blue hair. Who cares?' So I went to school with that, I went to my job. I taught with these funny wigs. And my students loved them.

I wanted to lighten up the mood, too. And if somebody asked me, I'd just say, "Hey, this is once in a lifetime opportunity. Let me make something good about it. "

Laura: Hey, I'm Laura, your beauty consultant. Need a breakdown of your wig options before you shop for a new 'do? Here are your three main types.

Real hair wigs. These wigs are made from human hair, so they're usually more expensive. They cost around 2,000 dollars. Because it's all human hair, you can use curling irons and blow dryers to switch up the style.

Synthetic wigs. These are generally more affordable, around the hundred to two hundred dollar range. They're also lower maintenance, because they're made from synthetic material. You can't use heat to style synthetic wigs. But they will maintain their style, even after you wash them.

Halo wigs. These are great partial wigs that you can attach to hats or scarves to have some hairs peeking out, like bangs, ponytails, or ends along your neck. Wigs can get hot or itch, so these partial hair accessories are nice to have more breathable options.

Caitlin: Finding a wig can be downright daunting. So we stopped by J. Crager Alternatives Wig Shop and got the 4-1-1 from the owner, John Crager, the owner, on what to look for when shopping for a real or synthetic wig.

John Crager: How are you? I'm good. I'm being interviewed.

Emily O: When we arrive at John's quaint Northwest side salon, you can see his smile through the window a block away. He's just bubbling with energy and enthusiasm. From his background as a hairdresser, to helping people going

through medical and natural hair loss over the past 13 years, John's finally found his passion.

John: So, yeah, this is my grandmother, here. From 1932. And that's her license. Now, on my business cards, I have put down that I am also a registered beauty culturalist. Which basically means I'm cultivating beauty. Yes I am. And I do it regularly. I like it.

Emily O: To help make the daunting process of wig shopping a little easier, John makes you laugh. Genuinely. It's as if all the scary parts of this process get diffused.

John: There's me and then there's talking about me, and I'm good with either. Yes, so I mean—I lost my train of thought, which is sometimes a very short train. Engine, caboose. There it goes.

Emily O: Then he shows you how much he cares—and I mean, really cares—about hair and about his clients. He provides women with so much more than just wigs and styles. He helps them find their freedom.

John: You know, but when a woman stands up, and she starts to cry, because I've given her her look back, so that she can go and take care of herself, and she can go to work, and she can take her kids to school, that's my goal.

Emily O: From cuts to color, resizes to repairs, and diagnosis to regrowth, John and his team help guide his clients through every step of the process.

John: There's all kinds of hair to get. Everything from obviously human and synthetic. People walk in and ask—"What's the best product? You know, I heard synthetic is horrible, and human is fabulous." And someone else will come in and say, "I heard human hair is horrible and synthetic is fabulous." It's only fabulous if you know how to work it. You can do a lot with them, believe it or not. Washing—

Female: —That's a pretty one—

John: —Yeah it is, isn't it? This is a—this was—I just did the lowlights on it last night. I know it's amazing. Isn't it? Look at this. It's just craziness. Now, if I want to sit there and take this—and again, to smooth it out—that was a spray bottle. So.

Emily O: So, if I'm a new person to your salon, and I'm about to go through chemotherapy, walk me through what the first consultation and my process of choosing a wig, and options, and all that stuff. What is that like?

John: You go through the process. I'll talk about when the hair is going to release. How it's going to release. Because it's not going to be something where you're going to wake up one morning and all your hair is going to be on the pillow. That doesn't happen. The hair does start to release, and it's very diffused. You may get a tingling sensation on your scalp. You may get a sensation that your scalp is very sensitive, like almost when it's been sunburned. And it's like a'—ow.' It's kind of '—ooh.' I'm brushing my hair, and it feels a little '—ooh.'

That's the precursor to the hair starting to release. That can take up to—depending on the amount of hair and all the other qualifiers—it can take up to two weeks before people may actually see a difference in your hair. And a lot of women want to know, well when—when should I shave my head? When should I do this? And that's, again, that's—I tell people it's really up to you. Because you need to be comfortable with that time, that it's got to happen. But I tell them, also, it's like, don't do it by yourself.

Emily O: So how do you help someone choose between human hair or synthetic wigs?

John: It really depends on what a person likes to do. And that's what I tell people. It's—there's two—there's two real qualifiers that I have people think about. One is, do you like doing your hair? I mean, do you enjoy styling it? Do you enjoy curling it, or flat ironing it, or changing the part, or making it a different look? If that's what you like to do, and you like it, and you're good at it, then you need to go with human hair.

If you don't like doing your hair, human hair is going to be a nightmare for you. So why do that. You don't need any additional aggravation. And I tell women, when they're—when they're looking at color, think about your tonal factors. You may want to get a little bit warmer, with some more gold tones in it, because that will give you a little more warmth, as your complexion may not be the same in six months, because your skin tone is qualified by melanin, which is in your skin. Your skin is not going to produce the same amount of melanin because of what's going on with treatment.

Emily O: How long does a wig last?

John: Generally, depending on use, a year and a half, two years. Now, I've had people who burn them out in three months. And I've had a woman who came into my salon, and she'd had the hair for five years, and it looked like she never wore it, and she wore it every day. So it all varies.

Emily O: And what are common ways people mistreat their wig? Like, what is a problem you see often, or what—if you could talk to a hundred wig owners right now, and say—

John: Comb your hair. Right at the nape area, in the back. Right? That sits right along the neckline. That's a hot spot. Okay. Everybody—women especially—get really warm right at the nape of your neck. When you get warm, you perspire. When you perspire, it hits the hair. When it hits the hair, then it starts to lock together. And then they're not brushing it out. And then the next day they're wearing it, and more of that starts to lock together. Because if it all locks in the back like that, then they start brushing through when it's all tangled. I can't tell you how many heads of hair I get where the base, at the nape area—the hair is gone. Because they've been combing it out when it's been all tangled together, and you just start ripping out hair. So, yeah, brush your hair.

Emily O: And what are your tips for washing and maintaining your wig?

John: Generally, they should be washing once every two weeks. And that's if you're wearing it pretty much every day. But I tell people also, when you're working, and when you get home at night, take an alcohol wipe or a baby wipe. Wipe the inside of the cap out. So that's going to keep the inside of the cap fresher. It's going to get rid of some of that fragrance that may be building up because of perspiration and oil. And it'll just make it a little bit nicer.

A lot of women will take their hair and push it behind their ear. When they do that, now whatever's on your hand is going to be the oils, and that—if you're constantly doing that in the front, the front of the hair may start looking a little oilier or greasier. And you can use a baby wipe, just to go over the front of the hair. You don't have to wash it. Brush through it when you get home, put it on the stand to make sure that they air out properly.

Caitlin: You may lose your hair. You may not. But for some women, keeping their hair during treatment is a priority. For some, it's about privacy. For others, it's about maintaining a sense of self. Whatever your reason, there are new game-changing treatments that help prevent hair loss during chemotherapy. Namely, cold caps. But how effective is it? What does it entail? How much will it cost you? We talked to some cappers to find out.

Emily O: Nancy and Shirley are two best friends who met playing bridge in Minnesota and instantly bonded over their strong, can-do attitudes. Once they confided in each other that they were both cancer survivors, they decided to put their heads together and formed the non-profit Rapunzel Project, designed to bring awareness to cold cap therapy.

So what is cold cap therapy? Can you explain that?

Nancy: There are two names for this process. Cold cap therapy, and scalp cooling. In both cases, the concept is a device that's placed on the head at considerably cold temperature that protects the hair follicles from the flow of chemo drugs for a period of time and allows chemotherapy patients—help to save most of their hair.

Emily O: Shirley, do you want to share your personal experience with scalp cooling?

Shirley: Yes. I'd gone in for my annual mammogram, not thinking anything of it, and the next day, I get a call from my oncologist, said, "We need to have you come in and check this out." And I said, "I have breast cancer, don't I?" And they said, "You need to come in." And when you first get that message, it is a real shock to the system. That's your first hit. And then they said, "And by the way, you will lose your hair." I said, "Really?" And he said, "Yes. If you go through this treatment, and you want a 90 percent chance that this is not coming back, yeah. You need to do the chemo and the radiations." And I said, "No options?" He said, "No. No options."

So I went in, and I tried on some wigs, and I looked at myself in the mirror, and I thought, 'This is not me. This is not who I am. But if this is what I need to do to

save my health, I'm all in.' And so I started my journey, thinking that's what was going to happen. And then my friend had told me, "You need to talk to the cold cap inventor." He was Frank Fronda out of London. And he connected me with a number of women in the United States who had used it. So when was talking to these women, I really got excited. And, like my husband said, "Once you found out about the caps, it was like the little light turned on again inside your eyes." And that's how I kept moving forward with the process.

So I went to my oncologist, and I was fortunate to have an oncologist who was really on board with me. He later told me he never believed it would work. I said, "So you thought I was really going to lose my hair? And we'll deal with this crazy lady later." He said, "Yes, that's kind of exactly what I thought." So he was very, very supportive, which was huge for me, because if I at that moment in time had had any sense that he didn't trust that it was safe for me, or that I should do it, I would have backed off. Because at that stage you are so vulnerable that you are just in the hands of your oncologist. And it's so important that they are on board with you.

And so away we went. And I remember by the time the third round chemo treatment came along, and I walked into that room, the nurses were lined up. They looked at me with tears in their eyes, clapping. They couldn't believe it. They were all stunned.

Nancy: Because they knew, by rights, she shouldn't have a hair on her head. At this point in her chemo. And she walked in with a full head of hair. And it was real—I frequently say it was a true goose bump moment. Because these are medical professionals. So for them to realize that this was actually efficacious was shocking.

Shirley: And that's when we just said, people need to know about this. We need to allow people to know that they have a choice. Because I just know the difference in the feeling that I had. It was about my right to make a decision whether or not to keep my hair, or not. There is nothing wrong with either decision, but the choice really made the difference. I didn't get to decide to have cancer. That was not my decision. And so this was the turning point for me. Once I knew I wasn't going to have that side effect, I'm not defined by this.

Nancy: It's not for everyone, but you can't make a choice if you don't know you have a choice. And this choice was not being offered to people, and people were not being made aware of it. And we felt that that was really a disservice to patients.

Emily O: Can you speak in the most general and simplified way, the difference between the two types, or what the options are, of the cooling caps?

Nancy: Okay. So there are two ways to apply this cold technology. The original way are what we call manual cold cap. It's a cap that's frozen in dry ice, or in a biomedical freezer. It's placed on your head. That cap has to be changed for a new cold cap generally 20 or 30 minutes because the body and the room temperature both warm the cap up. You generally use those caps for 45

minutes to an hour before the infusion starts to constrict the blood vessels. You use them throughout the infusion, and for a period of time after the infusion depending on what drugs you've had and what the provider thinks is going to be best for thick hair, thin hair, whatever.

The second system is the machines. The concept is that you have a cap that has tubing in it, that is hooked up to a machine that chills a cold gel type substance and pumps it through the tubing in the cap, circulating that same gel at the same temperature.

Emily O: I want to get a realistic view for the listeners of what it's like.

Shirley: So when I had that first treatment, I remember that cap coming on, and it was cold. It just was cold in the first three, four minutes, and then it would start to not affect me anymore. I was fortunate. I didn't have any reaction to it, really, whatsoever. So it was absolutely very doable to me. Was it comfortable in those first few minutes? I would absolutely say it wasn't. But I would just take my mind, and I would go someplace like, warm. And I would think warmth.

Nancy: And I—obviously, different people have different cold tolerance. There are people who can't—cannot continue because they just cannot get there. And it's—it's basically whatever you can do to make it comfortable. Cost is an issue for a lot of patients. We are seeing some insurance paying. Some amounts. But it's spotty and erratic, because not only does every insurer have multiple plans, and different plans have different benefits, but then every state has different regulations.

Emily O: You mentioned you had a team. Describe the process.

Shirley: The process was, we needed these caps to be at a certain temperature. And then we needed a laser thermometer to measure that—the temperature, to really shock those hair bulbs into hibernation. And so we would just get the cap out of the freezer, and—but the caps—you'd take them on and off every 30 minutes. We would put one cap on, take another cap off—you know, that's the way the process worked.

At that time, we had a number of people. We would fine-tune it. We had somebody with a stopwatch. We had somebody making sure that I was drinking water. I mean, we just had a whole crew in there. So there was always something going on. And I never even thought about the fact that this chemo is coming through my system, because there was so much good energy. Because everybody wanted to learn about it. Everybody was excited about it. Because everybody wanted to be a part of this.

If we could change the look of cancer, they wanted to be a part of it. And you just simply didn't need that many people, but it was just fun for everybody to be involved.

- Nancy: We were actually kicking people out. I mean, we literally had a—there was a fight for a spot on Shirley’s chemo team.
- Shirley: It really was a fun day. If any kind of a chemo day could be a fun day, it really was a fun day. And I remember sitting there, and thinking, ‘Oh that’s right. All my friends are here, and my family. Oh, that’s right. That chemo is coming in to my body. I wonder how I will react?’ When I got to that sixth round, I mean, it was like celebration, but it was like, ‘Oh, my word. This is so sad. Because now we don’t get to do this again.’ And I’m thinking, ‘Okay, guys, but I was the one going through this. I am really done with this.’
- Nancy: Right. Right. It wasn’t—I mean, a chemo—we say chemo party, chemo is never a party. But there was enormous support and love for Shirley in that room, and that was pretty special. But I think it goes back to everything that Shirley is saying about—there is an enormous amount of evidence that if you look better you feel better. And if you feel better, you heal better. It’s all about the whole holistic side of health and medicine. And mental state is an important part of the recovery journey for sure?
- Emily O: What are some of the services the Rapunzel Project offers?
- Shirley: We want to make people aware that this technology exists. We want to help them find out how to access this technology and give them as much guidance as we can on how to afford it. We don’t have the expertise to say, “This is your protocol with your drugs.” We don’t want that expertise. We want people who do this every day, who work in the clinics, work with the patients, work with the doctors and the nurses, to be the experts.
- Info@RapunzelProject.org is our email address. If you reach out to us, we would be more than happy to testify or Skype or phone call, or write a letter, or whatever we can do to help endorse the importance of this project for the overall holistic approach to getting a cancer patient well again.
- Nancy: When you’re the one going through it, you know that everything is happening to you. And that chemo is coming into your body. And you need to be an advocate for yourself. You need to make that decision, what is best for me. You can gather the information. That’s what your doctors and your nurses and your helpers are out there for. You can gather that information, but ultimately, you need to be the authority of your own body. Your own life. Your own path.
- Emily S: Hi, everyone. It’s Dr. Emily. Even though cold caps have been popular in Europe for more than 20 years, they’re still not widely recommended in the US. Since cold caps are designed to prevent chemotherapy from reaching the scalp, some doctors are concerned that they may leave behind cancerous cells. Although the first cold cap was approved by the FDA in 2015, more studies are needed to conclusively determine their safety and efficacy. Talk to your doctor to discuss your options, and then decide what the best course of treatment is for you.
- Caitlin: Thanks for listening. Be sure to rate and subscribe and tune in next time to hear:



Female: I channeled it into anger. Because someone has given you a raw deal. And unfortunately with cancer, there's no one to blame it on.

Male: Loneliness impacts our immune system through the stress response in our body.

Female: There's a giant network out there of women helping each other.

Female: You're teaching yourself that just because everything's awful doesn't mean that you need to always feel awful. You have a level of control over that, and you can—you can do what you can to better your current state, and therefore, I think, better the state of others.

Emily O: Special thanks to the survivors for sharing their stories. This Walgreens podcast was clinically reviewed by Emily Schafer. It was written, reported, and produced by me, Emily Ornberg, with Taylor Banasik, Lauria Locsmondy and Stefan Clark. It was co-produced by Caitlin Kiernan, author of *Pretty Sick: The Beauty Guide for Women with Cancer*. Follow her on social media at @CaitKiernan. Recording and mixing by Matthew Lejeune, with Connor Boyle, at Chicago Recording Company. For more oncology side effect help, visit [Walgreens.com/FeelMoreLikeYou](https://www.walgreens.com/FeelMoreLikeYou) to find oncology trained pharmacists and beauty consultants in your area.