

Support for Yale Cancer Answers comes from AstraZeneca. The Beyond Pink Campaign aims to empower metastatic breast cancer patients and their loved ones to learn more about their diagnosis and make informed decisions. Learn more at lifebeyondpink.com Welcome to Yale Cancer Answers with doctors Anees Chagpar and Steven Gore. I am Bruce Barber. Yale Cancer Answers features the latest information on cancer care by welcoming oncologists and specialists who are on the forefront of the battle to fight cancer. This week, it is a conversation with Caitlin Kiernan, a breast cancer survivor and author of the book "Pretty Sick: The Beauty Guide for Women with Cancer." Dr. Chagpar is an Associate Professor of Surgery and the Assistant Director for Global Oncology at Yale Comprehensive Cancer Center.

Chagpar Caitlin, I thought we would start at the beginning, when you were first diagnosed with cancer. Tell us more about that whole experience and the journey that you went through.

Kiernan I think that probably it was very similar to other women. It is very surreal. Everybody has their specific experience. I was falling asleep one night, I had very small dense breasts, and as I was falling asleep I rolled over, and my arm grazed against my breast and I felt a little nodule, like a lump and it is exactly what they say. It was a pea-sized lump, but I come from a family of women with cystic breasts and was used to having some lumps and bumps, so I waited to go to my doctor. I waited a month because I thought maybe it was a hormonal thing and after a month, it was not gone, so I went and she sent me in for a mammogram. It did not show up on the first mammogram, it did not show up on a second mammogram 2 months later, and so when I was at the hospital for the second mammogram, I insisted that they give me a sonogram. I literally waited 4 hours while I got an emergency approval from my insurance, I really went rogue on the hospital staff, but within 2 minutes of them starting the sonogram, they found 3 lumps, 2 in my right breast and 1 in my left breast.

Chagpar And then what happened?

Kiernan And then, the journey begins. You get told to meet with your surgeons, which I thought was weird because I think most people do not realize you have to meet with a surgeon before you meet with the oncologist, it is sort of backwards and it kind of threw me for a loop, and you are just immediately in it. You are meeting with doctors, you are hearing terminology you have never heard before. It is a very overwhelming experience and you try to sort through everything you are hearing to find your right medical team and that is how it began. I was very lucky that as a journalist, I knew a lot of people, so I immediately put out e-mails to everybody saying, who do I need to be seeing, who are my doctors, and I made appointments with a bunch of different surgeons, and I really did interview people, and I do not know if it was because I was so

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nervous about my health and the diagnosis or if I was worried about physically

getting the best result because we're talking about the main anatomy of my womanhood and I was young and single, but I did it like interviews, I interviewed these doctors and then I found the one that clicked, and it is not only about the expertise that they bring, oftentimes it is your connection to that doctor, and I never discount that because you are beginning a long-term relationship with this person and it is really important that you feel like you're heard and you feel like you get the explanations you need and so I was very blessed that I met Dr. Elisa Port who ended being my surgical oncologist at Mount Sinai in New York City, and she then gave me a list of plastic surgeons that she worked with and I interviewed them and found the one that I liked which was Dr. Leo Keegan, who was amazing, and that is sort of how it begins.

Chagpar And so, you had your surgery and reconstruction?

Kiernan Not immediately. I did a lumpectomy. The plan was to do a lumpectomy with chemo and radiation, and I did the lumpectomy, I did the chemo, and when I got to my radiation appointment, they told me they were going to have to probably radiate the top part of my right lung because of where the tumor placement was, and I just got very nervous. They told me all the side effects that could happen because of the radiation, chronic pneumonia, and it just seemed like I am making matters worse, and so at that point I decided to opt out and do a double mastectomy. And my doctors were great. My oncologist said, well this will be the first time anybody has changed their protocol in the middle, but he said it is your life, you have to do what you feel is the best plan for you and everybody was completely supportive and wonderful, and I am glad I did it. I have never looked back and said I regret that at all. Reconstruction and everything is a very weird beast, but I can sleep at night because of it.

Chagpar I think a few things in your story are so important – one is to advocate for yourself and do your research and the other is to really follow your heart in terms of what your decisions are because ultimately it is your life, your body and you need to be happy and comfortable with the decisions that you make. Where along this journey did you come up with the idea to write a book? I mean, was it just the experiences that you went through and then reflecting upon them that got you to the book?

Kiernan I never really intended to write a book. When I was going through treatment, as each thing happens, as you start chemo, as you start having your surgeries, I would of course start to look up what I needed to worry about, how was my skin going to heal, what was chemo going to do to my hair and my eyelashes and my nails? And the first protocol that was suggested to me for my chemo regimen, I was going to possibly lose my finger nails and I was going to have to do gel therapy and I was so nervous about

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that and I had no idea what it was, as most people do not, because why would you need to know about that? And so, as a beauty director for a magazine, I just

started calling all of the people that I interviewed, I would call the dermatologist that I talked to and I would talk to the celebrity hairstylist, manicure assistant and ask, what do I do, how many days do I have before my hair starts falling out, what am I going to do, how do I protect my nails, what do I do about my skin? I started getting a lot of hives, I was getting very dermic, I would get acne and my skin was turning really red like all the things that can happen to you during chemo and while it was happening, because cancer treatment has come so far, people can go about their normal lives. So, I was at work. I was going to work and I am like I need to look presentable, I still need to kind of pull it together enough to do my job and not be distracting not only for me but for other people around me. It was not until the end my treatment that I was hearing from people, oh I did not realize that you were sick or the people that did know would say, you are amazing, you have really been able to self-care and it is impressive because there is a lot going on, and then I started thinking to myself one day during one of my chemotherapy sessions, I thought to myself, I do not know what the women, the single mom without health insurance living in a part of our country who does not have access to great healthcare that I do, what is she doing right now, how was she taking care of herself and able to survive this journey emotionally and physically, and I thought I just need to pay forward all of my blessings, I need to put it in a book and put it out there in the world because all of this information was not in one place, and it is amazing how many little things can make a huge, huge difference in just how you feel. Mouth sores for example– they are so painful and they can cause you problems with eating, and if you are not eating, you can cause your treatment to be delayed, but there are mouthwashes that are off protocol, that help immensely. So, to me, it was really important for me to just get this information out there to help the other women on this journey.

Chagpar And you being a beauty director of a magazine, for you physical appearance was very important, but I think for other women going through the cancer journey, how they look is often very much tied to how they feel as a woman and as a person going through this.

Kiernan Yeah, and I think when I started to ask the question, you know for me I was very concerned about how my reconstruction was going to appear. And I think most women are, but I feel like sometimes women do not feel like they have the right or they feel like they are going to be judged in that and even when my hair started falling out and I would say to my doctor, you told me I was not going to lose all my hair and he would be like, it is not my job to worry about your hair, I am trying to kill this disease

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and I totally get what he is saying, it is not his job. His job is to care for the cancer, to get the cancer out and increase my possibilities of living, and so I do not marginalize that when people are like, do not be focused on that, but I think because it is so tied to our self-esteem and our ability to kind of put a spring in

our step, it is hard enough when you really start to become so detached from your body because your body is changing on you. It was a surreal experience to look in the mirror every day and not recognize the person looking back at me, and I am like how do I carry on in the day when I do not even recognize who I am anymore, and you are worried about so many things that if you can just look good when you walk out the door, that paves the road for the rest of the day, the day after next, it really is I cannot underestimate how important it is and it is not a vanity issue in my opinion. It really is an adjunct therapy in my opinion. And I think I am hearing more and more, since the book came out, I hear from so many people saying you are absolutely right. Like, when I was able to draw on an eyebrow that looked like an eyebrow and I was not self-conscious about it, I was able to just focus and do what I needed to do and it is just like – you know, it is little things that really add up and make a difference.

Chagpar It is almost like giving yourself a sense of normalcy when things have gone abnormal with a cancer diagnosis.

Kiernan Yeah.

Chagpar So, let us talk a little bit about some of the things that you experienced and some of the ways, the tips that you bring out in the book that have kind of helped you in your experience to give our listeners a sense of the things that they can do, small practical tips that people who may be going through cancer have to face. So, one thing that I think that most cancer survivors deal with, at least when they are going through chemotherapy and one of the biggest concerns that we all hear is, oh my God, I am going to lose my hair.

Kiernan Yeah. You know, it is fascinating for me to learn upon interviewing all these oncologists that it was the after relaying a diagnosis, it is the first question oncologist gets. So, to me that says a million things about the concern and it is not a vanity concern, it really is about like what am I about to, you know how rogue is my body going to go on me and what do I need to do? So, there are a lot of tips with that.

Chagpar You know what, we are going to learn all about those tips right after we take a short break for a medical minute. Please stay tuned to learn more about beauty and cancer and get a lot more tips from our guest, Caitlin Kiernan.

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combination of 5 different chemotherapies is the latest advance in the treatment of metastatic pancreatic cancer and research continues at centers around the world looking into targeted therapies and a recently discovered marker HENT-1. This has been a medical minute brought to you as a public service by Yale Cancer Center. More information is available at YaleCancerCenter.org. You are listening to Connecticut Public Radio.

Chagpar This is Dr. Anees Chagpar and I am joined tonight my guest Caitlin Kiernan. We are talking about her journey with breast cancer and her book *Pretty Sick: The Beauty Guide for Women with Cancer*. And right before the break, we were talking about how it is really not vanity, this idea that women going through a cancer diagnosis want to look and feel normal. And it really gives them a sense of ownership over their bodies when in a sense you feel like you kind of lost some of that ownership when you have been given a cancer diagnosis and now have to face treatments that cause hair loss and nail darkening and on and on and on and on. We were talking about one of the biggest concerns I think that we all hear when anybody hears the word "chemo," the first question is always, oh my God, am I going to lose my hair? So, what are your practical tips and advice about that? Did you go through that and how did you overcome it?

Kiernan Obviously it was the first question I asked after getting all of my information from my doctor. I immediately reached out to my hairstylist and I was like alright this is what I am up against and my hairstylist at that time was Ted Gibson, who is Angelina Jolie's hairstylist, and he said to me that the most important thing is to have a game plan, you have about 14 days and it generally happens right before your third chemotherapy cycle that hair will start to fall out, I think it is different for everybody, but it is sort of in the same range, and he is like get ahead of it, have a plan, cut your hair short because there is really nothing worse than waking up and having clumps on your pillow or having it fall down the drain, and when I interviewed Joan Lunden, she said the exact same thing. She was like, you really need to just get ahead of that, all of this stuff is like

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you were saying before, it is not really about vanity, it is about taking control over a situation that is spiraling out of control. There are very few things that you can control when there is a cancer diagnosis, but there are little things like being able to go in and get your hair cut into a cute sexy-pixy and have fun with it. My plan was to get the pompadour haircut that Rihanna got because I always loved that hairstyle and I am never going to do it again, and now I have an excuse to do it. And so, that was my plan. And I had gone wig shopping with Ted because you really want to look for a wig while you have hair so the person in the wig shop can look at your hair, look at how it falls, look at your texture. You know, there are some people that just want to go, get a long blonde wig or do a fun wig, but I think 9 times out of 10, it is so jarring to lose your hair to

begin with that you are better off just replicating what you have until you are comfortable wearing wigs and sort of ease into it a little bit, and so that is what I did and that is what I suggest to people. As I always say, have a plan and go get your haircut in increments, maybe do a bob first, then the following week as more hair is falling out, you can go and get a cut in and by the time you buzz, it does not feel so drastic, you do not feel this huge clump of hair or see this huge clump of hair falling, it really is less sad. And wig shopping, it takes time if you get a custom wig, but I do not even advocate for custom wigs. People are big on the custom wig-thing, but custom wigs are high maintenance, they are real hair wigs basically is what they are. They are very expensive. They can cost thousands and thousands of dollars, and they are very high maintenance, you have to wash them like real hair, you have to blow dry them on your head without them pulling down and it really is a lot of work. I think why a lot of women tend to want a real hair wig is because they look like real hair. They have this scalp part, the weft of it looks like a real scalp, so it just looks like real hair and when you are wearing a wig, you want to look real and a lot of women do not know this, there are synthetic wigs that have the weft that looks like a scalp and there are combination synthetic real hair wigs where the front is real and the back is synthetic, so you do not have to worry about the sweat causing it to fray, and I go through a lot of the different types of wigs in my book because I think a lot of women feel pressured to get the right wig and it should not be an added pressure in this tough time. It should be easy where you are having information, I am busy, I shower a lot, I want to be active, a synthetic wig is better. If you are Joan London and you are on TV every day, you need a real hair wig, okay fine. But, most women do not need that. And so I am a big advocate for telling women to save their money, to save the stress, to make it easy on themselves. And when you go wig shopping, you want to bring someone who is informed and who is going to tell you the truth because you really do not want to walk out with that long blonde wig, looking like Kim Kardashian because you are going to feel ridiculous in two days.

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Chagpar And when you talk about the expensive wigs, I think that this is another thing that people really do not think about upfront. Is it covered at all by your insurance?

Kiernan It is interesting. When I called my insurance was going to give me like 50 dollars. It was so insanely low. If you are talking about a real hair wig, you are talking about a wig that starts at two grand and can go up to 10 grand. It is just unaffordable. But in some, and I got this tip from one of my dermatologist friends who was a breast cancer survivor, in some insurance policies, there is a clause for gadgets and devices and wigs can fall under that. And a lot of people do not know that. So, it is really important for you to know your insurance policy and kind of figure out if it will not pay for a wig, if you claim it under that, which I found fascinating. I wished I had known that

because my dermatologist friend got 500 dollars for that. That makes a huge difference for a lot of people. But, you can get really great synthetic wigs for 150 dollars. I would say, stay away from like the 30-dollar wig. You are going to be wearing this for a couple of months, your head is going to be sweaty, it can get itchy, you want to be comfortable and at the end of the day, you want to feel comfortable, you don't want to feel self-conscious and you want to physically be comfortable.

Chagpar And I think the other thing that people always think about when they think about hair loss is the hair on the top of their head, but what a lot of people may not realize is that the hair all over your body disappears too, so that is eyelashes and eyebrows and everything else. Talk to me about how that impacted you and what you did about that?

Kiernan Honestly, that was the scariest thing for me because even though I was concerned about my hair falling out on my head, I was more concerned about my eyebrows because I am going to look like an alien, I am going to look like the twitter egg with no defining hair on my face and it is hard to draw. I am not an artist, it is hard to draw an eyebrow on a given day when I have hair. How am I going to do this? And I turned to my friend, Ramy Gafni, who is a cancer survivor and a makeup artist, he has done makeup for you name it, every celeb, he has done their makeup, and he gave me great tips. He told me you really want to look for certain types of brow products, one that is a wax and a powder base because the power will go on and the wax will sort of seal it onto your skin, so even if you start having hot flashes, which tends to happen or if your body temperature changes, your brows are going to stay in place and it is easier to control putting them on and I give a step by step on how to gauge the anatomy of your face with the high point of the eye bone, eye socket, and how to figure that out and it takes a minute. Let's be honest, we are not used to doing our make-up professionally

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like that. I certainly was not, and I am in the industry, so for me to even say that, so I give a step by step and I feel like that helped and a lot of people have said that it was a good guide because they never realized how to do it before.

Chagpar And what about your eyelashes? For a lot of women, just losing those eyelashes, normally they do not really think too much about it, but for some people it is really problematic.

Kiernan It is problematic. The short-term fix is brown eyeliner and what that does is if you gently line the top of your eye, your lid, it gives you that definition, it frames your eye and creates that depth field that you would get from eyelashes until you can get approval from your doctor to use something like Latisse which does help and I encourage people to do something like that or Viviscal once it is approved by their doctors and they get the okay to use it. I mean my doctor at the tail end was like go-ahead and use it and start getting your lashes growing.

I do not think a lot of people realize that your lashes will come back and then in like 2 months they fall out again and then they come back again. So, it is just sort of the cycle of the hair growing back and getting chemo and my hair was never the same once it came back. It has been this bizarre texture and it is the same with your eyelashes and the hair all over your body. It just comes in differently and it takes time and it is fun.

Chagpar And then, what about your nails? A lot of people who go through chemo have effects on their nails, either their nails fall out or they turn black, and I mean it is a visible presence.

Kiernan Right, it is visible and this is what is interesting about nails because nails grow at such a slow rate, you really do not notice the changes until 2 months down the road. I got indentations and lines in my nails even though my chemo protocol had been downgraded from the one that I was going to lose my nails, it is still a cell in your body, it has been affected by the chemotherapy agents in your body. So for me there is not a lot you can do with nails. It is a tough situation. What you can do is to make sure to keep cuticle oil on them, make sure you are using your hand cream. It sounds basic, but it actually helps with keeping them hydrated, keeping the cells moist, the matrix of the nail is a very important part so you have to just be very careful and gentle with it, and for people that are losing their nails, it is important to just keep them wrapped and talking to your doctor because there are certain washes you can do, you probably know more about this but there are certain washes you can do on your nails just to keep the bacteria at bay.

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Chagpar Yeah, you want to keep them clean as much as you can. The other thing that I think a lot of women struggle with, with chemo and with radiation is skin, skin getting dry, skin peeling. How do you deal with all of that?

Kiernan I mean it is hydration. But to me, I made it a big point in the book to talk about using products that are science backed and evidence based. In the cancer community and I am sure you are familiar with this, there is a big organic versus nonorganic debate, and I am all about using pure ingredients when you can, but sometimes those natural ingredients do not have the science and the delivery systems that a drugstore cream might have. A perfect example of this is oats and when you have hives and inflammation and sensitive skin, it used to be that your parents would throw you in an oatmeal bath to calm all of that, but there are brands like Aveeno that have been able to isolate the molecule that helps and so you can take a bath and it is efficient.

Caitlin Kiernan is a breast cancer survivor and the author of the book "Pretty Sick: The Beauty Guide for Women with Cancer." If you have questions, the address is canceranswers@yale.edu, and past editions of the program are available in audio and written form at YaleCancerCenter.org. I am Bruce Barber

reminding you to tune in each week to learn more about the fight against cancer here on Connecticut Public Radio.