

Second Opinion with Joan Lunden

The Cancer Spouse

ANNOUNCER: When our communities need help, Blue Cross and Blue Shield companies step up with partnerships capable of preparing meals for thousands of families in need, because it's not just about health insurance. We believe it's our responsibility to expand care to rural communities, protect our heroes with safety equipment, support local nonprofits. These are our stories to help build stronger communities for the health of America.

ANNOUNCER: "Second Opinion with Joan Lunden" is produced in conjunction with UR Medicine, part of University of Rochester Medical Center, Rochester, New York.

JOAN: Breast cancer is the most common cancer among women worldwide, and this diagnosis not only brings physical changes, but significant emotional and psychological challenges as well. I know firsthand that breast cancer is not something that you want to face alone. If you're married or in a committed relationship, your spouse or partner will feel the impact of your diagnosis right along with you. And his or her life will forever change right along with yours. And their support can be crucial to your recovery. Today, we take on the topic of the cancer spouse. Joining us is our primary care physician, Dr. Lou Papa, from the University of Rochester Medical Center...

LOU: There's people depending on you and it was -- You know, as a husband, you just step in line, say, "Okay, what do I got to do?"

JOAN: ...Lou's wife, and breast cancer survivor, Sue Papa...

SUE: The eyebrows, the eyelashes, the hair is gone, and it's a very strange thing to go through. It is, and it really affects you.

JOAN: ...Dr. Marisa Weiss, practicing breast radiation oncologist and the chief medical officer, founder, and visionary behind breastcancer.org...

MARISA: Just to keep communicating and checking in with each other to see where you are and let your partner know what you need and to get those needs met through the village of people in your life.

JOAN: ...and my husband, Jeff Konigsburg, will also be joining us.

JEFF: But as a spouse, when you hear that news, you just don't know how to protect the person you love.

JOAN: I'm Joan Lunden, and it's all coming up right here on "Second Opinion."

JOAN: When a spouse is diagnosed with breast cancer, the couple's relationship can change. Breast cancer is happening to both of you, and you will face the cancer challenge together. So we are so happy to have all of you here today, and along with my husband here. You know, "Second Opinion" viewers have come to know and love Dr. Lou Papa over the past 16 years. But of course, there are things that he doesn't necessarily share on air. But today, he is here with his wife, Sue, and we really thank you for discussing one of the most difficult times in your life. And this, their whole world pretty much changed nine years ago. And by the way, this is a great love story. I mean, you met in college, I think, at Hofstra.

SUE: We did, yes.

JOAN: You have three smart, beautiful children. Lou wrote that part. Just kidding. Nice emphasis. They've been married for 31 years. But nine years ago, they got hit with this news. You were the one diagnosed. Why don't you start us off soon?

SUE: Yes, thank you, Joan. I feel like breast cancer is just always in everyone's back of their mind. And the fear is always there. And unfortunately, I didn't really keep up with my mammograms. I was busy helping with my dad and my kids were being shuttled all over the place. So as you know --.

JOAN: Yeah, this is such a typical story.

SUE: It's so typical

JOAN: But you're important too.

Right, right. And so I felt something change in my breast. And I would do exams now and then, like all of us. And I felt something change, and it wasn't really a lump. It was more of a thickening in my breast. And so I wasn't quite sure. And my husband's like, "Well, let's get it checked out." So I did, and the radiologist was not that concerned. She's like, "I'm not really sure, but we'll do a biopsy and see what happens." And of course, we did, and she thought it possibly was something else. And we then I got the phone call, waiting, thinking everything's fine, and she called, and the first thing is, she says, "Are you sitting down?" And that's when you're kind of your world just kind of implodes. And that's when she gave me the news.

JOAN: Do you remember that moment when she -- I mean, you're not just the husband, you're a doctor. And she says something isn't right.

LOU: I remember the exact moment, Joan. It was the end of the day. We were both lying in bed just about fall asleep. And I could just tell, you know, as you can with a spouse, something's wrong. And I said, "What's wrong?" She goes, "I felt something on my breast today." And she goes, "It's not a lump, it's just a thickening. I think it should be okay, but I want to get it checked out." I could just tell from her tone, I just had -- just had a bad feeling about it. And she's had cysts over the years. She's had lots of cysts,

like a lot of women do. So there's multiple times that they've seen stuff, they go for the scary "Come back in" type thing, and it's always been okay. This time, for whatever reason, it just felt different.

JOAN: And you had a sense of that, so when Sue got that call, I mean, you're not just a husband. You're also a doctor. You can't make light of it. So how did you help navigate this?

LOU: It was a blessing and it was a curse.

JOAN: Yes, I'm sure.

LOU: So it was a blessing in the sense that, you know, I can understand the information. I could get stuff done. You know, whatever needed to get done, I could talk to people and say, you know, "This is my wife." This is where you pull that card out. But at the same time, it's kind of built into, -- and I don't know that you necessarily have to be a doctor for this. It's just part of just being a husband and a father. You just felt like you needed control. You just felt like you needed to be strong for everybody, need to feel like you have to drive the bus. And a lot of times, you didn't kind of address your own emotion about this. Like, "My God, my wife, the mother of my children has breast cancer." And even though you're a clinician, I was just still scared as hell.

JOAN: Well, you know, I have to admit that as a health advocate, I just felt like when I got this -- First of all, I found out that I had missed a couple of years, and I -- Come on, you know? "You're, like, out there telling everybody to be healthy." I remember when I got the -- First, I had a 3-D mammogram the day of my diagnosis, and it was clear. And just by chance I had the ultrasound. And it was only because I had been sent on a story about mammograms, and I just chit-chatted with the doctor and said, "They're always calling me back." I'm the one that gets called in for more pictures. And you get so panicky when they do that. You always say, "Why?"

Did you see something bad?" And they always said the same thing -- "No, it's just hard to see anything because you have such dense breasts." And I didn't know that that should have been a red flag to me because I didn't know about that yet, and I didn't know that that could obstruct the view of cancer in a mammogram.

SUE: Mm-hmm.

JOAN: But because I did that story, I went back to my gynecologist and said, "Add on an ultrasound." That's why I got that test that day that found my cancer, which was very fast-growing, aggressive. I just not only thank God I was sent on that story but that I listened to her and I came back and I acted on it. And, you know, the doctor, the radiologist wanted me to stick around to have the MRI biopsy right then. Because they say so often if they let the woman walk out of the office, they get scared and they don't come back. So I got in my car to drive home, and I called my husband. And it was maybe one of the most difficult calls I've ever made. It's like something's just stuck in your throat to say, "I might have cancer."

JOAN: And I'll let Jeff kind of pick it up from here.

JEFF: Well, the so-called routine mammogram, there is nothing routine about it. And you called me and you didn't even have to say anything, because I heard in your voice. And needless to say, you're an incredibly strong person. But just the tone of your voice before you went into any anything significant was something I'll never forget. And, you know, all I could say at that moment was, "I'll go back with you tomorrow and let's stay positive," which is something you do all the time anyway. And so you went and then we went back on Monday, and we were sitting with the doctor. And you received your diagnosis. But, look, it was overwhelming. But as a spouse, when you hear that news, you just don't know how to protect the person you love and you cherish. But interestingly, you made it easier for me, Joan, because your response to receiving the diagnosis was something

that I could never have anticipated. You looked at me literally upon hearing this news and you said, "My dad was a cancer surgeon, and he devoted his life to healing and helping others. And this is my opportunity to do the same." And that was immediately your response and that started your cancer journey.

LOU: And it's interesting what you have said. I think we both married very strong women, that's for sure.

JEFF: We're overachievers.

LOU: [Laughter] That's right. Because my wife, right from the beginning, the first thing she said was, "I'm sorry." You know, it's the mom thing. "I'm sorry that I'm putting this upon everybody."

JOAN: And I felt the same thing. I mean, it's probably not how we're supposed to --

No, but it was the first thing she said. And then she said, "Let's just get this done. Let's just get on track and get this done." And I think that part of it is that strength and there's people depending on you. And it was, you know, as a husband, you say you just step in, say, "Okay, what do I got to do?"

JOAN: And Sue, as the woman, I mean, you're -- if you have that same sense that, "I'm sorry?"

SUE: Yes. I felt it's my fault. I'm putting my family through torture. You know, the worst thing I was telling my kids.

JOAN: See, that's what brings the tears to you, right?

SUE: I know. I'm sorry.

JOAN: That's what brings the tears.

SUE: Yeah.

JOAN: Because we feel like, oh, my, gosh, we want to protect our children any way we can. I had a little bit of an added sense of responsibility and that I'd been a health advocate for so long.

SUE: Right.

JOAN: And I felt I was letting everybody down.

LOU: Right. How'd you deal with that? I mean, that's -- I mean, as a physician, having to deal as a physician has its own issues. And I'm sure everybody has it, but, you know, I'm not overstating to say when you went through your journey, you made it public, it was awe-inspiring, and I think it really helped a lot of people. But as a couple and as a family, how did you -- how'd you do that?

JOAN: You know, one of the hardest things I think was when People magazine wanted me to tell the story. And I was starting to understand that by sh-- we should share stories, because when we share important stories like this, other people can learn. But the idea of having my picture on the cover of a magazine like People.

SUE: Yeah.

JOAN: And I think what it was is, like, sure, children don't read People magazine, but their parents do. And what was going to happen when my kids go to school and would they say absolutely to my children, "We saw your mom bald on the cover of People magazine"? That just completely -- I was so worried about that. But the more we talked about it and the more we discussed what, you know, that kind of an impact could have on other

people, so I really didn't even know whether I was going to do it that morning when the crew came in from People magazine, the photographer and everyone. And we shot it with a wig. We shot it with a like a scarf around the head. And then I cleared the room and we shot it with my bald head, which was just so weird. And this was going to be the first time and it was going to be the first time -- what? -- in front of everyone. It was so scary, but I had to, like, dig deep down inside and put that smile on my face. And I'll tell you. Everyone reacted to it with the right vein, and I've had women come up to me. I'll never forget this one woman that said, "The moment I was hearing those words, 'you have breast cancer,' I thought about your People magazine cover." I was like "What?" She said, "Not your face, your smile."

SUE: Right.

JOAN: "The smile said to me, if you could conjure up that smile, then I was going to be able to get through this." So all of a sudden it was like -- it was all worthwhile.

LOU: Right.

JOAN: How did you feel?

SUE: Well, I just wanted to comment on your cover on People. I remember I was probably a few years ahead of you. I'm nine years out from my diagnosis, so I had already gone through my treatment. And I remember seeing the People magazine cover thinking, "Wow. This woman is so brave." And I was so very proud of you because you put a face to it, and, by the way, you look absolutely beautiful bald.

JOAN: Yeah, I was so happy I had an oval head.

SUE: [Laughter] Right. I also went bald, but I looked more like Uncle Fester from the Addams Family.

LOU: No you did not.

SUE: I thought you looked amazing, and it made me feel good -- not like, "Oh, great. Joan has breast cancer," but here is a public figure who's putting it all out there, and I was just really happy that you did that.

Well, we're all talking about that moment, that moment that will be etched in our memories forever. Dr. Weiss, there are a lot of really important decisions that need to be made -- you know, what kind of treatment are you going to do, to have a mastectomy, are you going to do reconstruction. How do you advise couples to kind of navigate through these really important decisions?

MARISA: Sometimes these strong women and men get, you know, paralyzed with fear, and sometimes people who are normally soft-spoken can rise up and find their strength. But when I'm sitting there with each individual in the hospital, I know there's only one of each individual, and she needs or he needs to figure out what her full life view is -- you know, how to get the most out of life, live a long and wonderful life, and basically each day be able to wake up and say, "I'm happy to be alive. I did everything I could that was reasonable and effective to get rid of this darn thing, and I'm going to do the best I can today to stay as healthy as possible." And in the context of someone like you, I review the extent and nature of the problem we're up against and then what we can do about it.

JOAN: And husbands should also or spouses should also understand some of the psychological changes that happen, like when you lose your hair and then your eyebrows and you look in the mirror and you're that real cancer patient. And I know we're seeing breast cancer, unfortunately, earlier and earlier in women, but for the most part, a lot of women are in their 60s and

they're going through menopause, and they're going through all kinds of other changes that can affect how they feel about themselves and their appeal. So what advice would you give about that?

MARISA: Well, absolutely. I mean, you don't feel like yourself, that loss of hair, the loss of a breast, being thrown into menopause early, being under treatment with side effects, just to make sure that the person has the information, support and the solutions, like a good wig or a fun turban or whatever it is to help her get through all of that. And then, as people are helping you along the way, as a breast-cancer patient yourself -- and by the way, I'm a 10-year survivor.

JOAN: Yay!

SUE: Yay.

I'm a dual citizen. But, again, you're not doing it alone, and your sharing your stories today is hugely helpful just to hear that Sue, for example, is nine years out. Wow, you look so good, and that that's possible for me too as someone out there listening and seeing, who's worried that that her life might end or she might no longer look good and that she might be damaged goods and not attractive or appealing to somebody. The fact is that you are still you and you got to kind of find your -- put the big-girl pants on, right?

JOAN: Yes.

MARISA: Find your strength, find out what gives you joy, comfort, support, and try to, you know, really maximize that in your life to help along the way through the bumpy ride.

JOAN: Well, while we are telling them to put their big-girl pants on, though, we don't want them to think that they should just be steady Eddie when

they look in the mirror and all of a sudden, your hair is gone. It's not a shallow thing. Your hair makes a huge difference.

LOU: Right.

JOAN: It frames you. When you lose your eyebrows and your eyelashes, it's like somebody took an eraser and erased your face. Didn't you feel that way, Sue?

SUE: Losing my hair was -- Well, part of my treatment was a double mastectomy. It was harder to lose my hair than my breasts, and I know that sounds crazy.

JOAN: Wow. No, it doesn't sound crazy.

SUE: And I knew it was coming. But I don't know what it is. And I'm not a vain -- I don't think of myself as a vain person. I don't really do a lot.

No, it's not about that.

It's not, but it's an outward appearance that your woman -- It's a part of womanhood, I feel like, you know, your beauty. As my mom used to say, your crown of glory was your hair and now it's gone, and there's no really hiding it. Like you said, the eyebrows, the eyelashes, the hair is gone, and it's a very strange thing to go through.

JOAN: Yeah.

SUE: But it really affects you.

JOAN: As a husband -- and be honest -- what was it like to see her all of a sudden with no hair?

LOU: It was not what you would think. It wasn't like, "Oh, my God, my wife has lost her hair." This is how you know you're really in love with the inner person. It really didn't affect me that much. And I'm not saying that like I'm this really deep person that -- it's just the way it was for me. I was so overwhelmed by the fact that this was happening and maybe it was me putting my battle gear on, you know, as sort of lieutenant in this army. It didn't affect me as much because I think I was just so concerned about how this was all affecting her.

JEFF: I'll tell you, I'm just listening to Lou and to Sue, I think that we are -- we share a number of things in common, not just spouses and breast cancer. When I met you, Joan, I instantly just fell in love with you and, you know, your outer beauty resonates. That's easy to see. The reality is, is that I was more focused on the times that you put your head on your pillow at the end of a night and you just need to hug each other because there's something going on, and all families deal with life events. You deal with financial setbacks. You deal with loss. You deal with illness. And so what attracted me to you more than your outer beauty was that aspect that I knew that I could put my head on my pillow with you at the end of the night and that we would find a way to make everything okay. And so now this was our time, and your loss of hair was not in any way unattractive. As a matter of fact, your poise, your conviction, your desire to help others was an incredibly attractive aspect of you, and it only enhanced our relationship.

JOAN: Dr. Weiss, you know, it doesn't -- we are maybe great examples of how it I think really strengthened both of our relationships, even though we had really strong relationships to start. But, boy, it's got to be so tough for some people. And sometimes a spouse has a really -- not that there's anything wrong with them, but they just have a really hard time...

LOU: Good point.

JOAN: ...dealing with the loss of hair, but more so the idea of having a mastectomy and are you going to look whole. This is hard for women too. How do you advise people on this, Doctor?

MARISA: Well, again, there's only one of each individual, and you have to ask her how she feels about these very personal, private, emotional decisions, and to -- it's up to her to decide how she's going to ask her partner their input. But, you know, it's so hard to keep these relationships going in an upbeat, proactive way where you're, you know, you learn new things when a diagnosis occurs. You know, the relationship gets better or stronger, and some areas may falter, and you try to sustain those good things moving forward. But the truth is also that the relationship is changed.

JOAN: I kept hearing from people on Facebook saying, "You go into cancer treatment one person and you come out another."

SUE: Absolutely.

JOAN: And certainly you have this new appreciation for the tiniest things. Interestingly, it also lets you find out how much people who love you actually do love you.

LOU: Yes.

JOAN: And it's a wonderful thing to discover that.

SUE: It can be overwhelming too.

JEFF: Well, my whole focus was you and our children. Nothing else mattered. So as a spouse, it didn't matter about me and my feelings, quite frankly, while they're relevant to some extent, it wasn't about my feelings. It was your journey and my being your co-pilot and assisting you any way I

can, throwing out all the rules, whatever we needed to do, and I think that was the way we managed through this.

JOAN: Well, believe me -- I think Sue would agree -- that we consider our spouses, that you were the forgotten heroes, you know, that you were really our superheroes. But, Dr. Weiss, I want to ask. When couples are struggling and they just feel like they're kind of falling apart during any stage of cancer treatment, what is your recommendation that they can do to get back on track as a couple?

MARISA: Right. I mean, just to keep communicating and checking in with each other to see where you are, let your partner know what you need, and to get those needs met through the village of people in your life, because not all partners have the capacity to communicate and express themselves or cook or do laundry or know exactly when to show up and when you want them to disappear. So you do need to sort of look at your whole village of people that are there to support you through this difficult journey, and also, it's important to recognize and notice when someone's helping you and to thank them and to let them know how much it really means to you. And then as you move through life, you know to celebrate that every day, that moment you have together, the beautiful sunsets, just feeling well one day, free of being tired, let's say, or sick or, you know, if you've got a good hair day or even your hair looks -- you have hair.

JOAN: Yes.

MARISA: It's something to celebrate.

JOAN: And, Sue, what advice do you want to leave people with? You know, what do you know now that you wish you would've known before your diagnosis?

SUE: I wish, going back to my past self, I wish I would have scheduled my mammograms regularly because this probably would have been picked up earlier, and to basically take care of yourself. Put your health a little bit further up the ladder.

JOAN: Yep.

SUE: Take care of yourself mentally, physically, emotionally, every way. Just take care of yourself.

JOAN: Further up that to-do list of ours.

SUE: Yes.

LOU: Number one, actually.

JOAN: Because we fall off our to-do list as everybody else needs us to do other things.

SUE: Right.

JOAN: But you can only be your best if you're taking care of yourself and getting all those annual checkups. Don't let them pass by, right?

SUE: Absolutely.

JOAN: Well, we thank you for sharing your story and, Lou, you don't usually do it this way.

LOU: That's right.

JOAN: And, Dr. Weiss, thank you so much and thank you for breastcancer.org. And honey, I'll see you tonight.

JEFF: [Laughter] I look forward to it.

JOAN: Alright. It was a great discussion today and one that I feel is really needed and one that we hope you will continue at home if you're going through a similar situation, no matter what illness you might be facing. And you can find more on our series at secondopinion-tv.org. You can also follow us on Facebook and YouTube, where you can watch today's episode and much more. From all of us here at "Second Opinion," we encourage you to take charge of your health care. I'm Joan Lunden. Be well.

ANNOUNCER: When our communities need help, Blue Cross and Blue Shield companies step up with partnerships capable of preparing meals for thousands of families in need, because it's not just about health insurance. We believe it's our responsibility to expand care to rural communities, protect our heroes with safety equipment, support local nonprofits. These are our stories to help build stronger communities for the health of America.

ANNOUNCER: "Second Opinion with Joan Lunden" is produced in conjunction with UR Medicine, part of University of Rochester Medical Center, Rochester, New York.