Rediscover Healing Through a Patient's Eyes Transcript

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Introduction and Ann Fonfau2019s diagnosis

Welcome to another episode of the Breast Cancer Breakthroughs Summit. I'm Dr. Véronique Desaulniers, better known as Dr. V, and your co-hostess So today we have Ann Fonfa for who was diagnosed with a lobular breast cancer back in 1993.

And she was also suffering from multiple chemical sensitivities. And so Ann, thank you so much for being with us and sharing your healing journey and some positive words of encouragement.

It's my pleasure. So tell us a little bit about your story, your pain to passion. I mean, you you were diagnosed with breast cancer and you chose to do a particular kind of treatment outside of conventional medicine.

So tell us tell us about your journey. So at the time that I was diagnosed in January of 93, there was no Internet for regular people, and I didn't know anything.

The only people I knew with cancer had died. And so I found a callus on my left breast at 2:00, by the way, subsequently discovered that left breast 2:00 is 50% of all breast cancers, which should be addressed anyway.

So I did what most people do. I went and got a mammogram and this woman, doctor who was doing it was all upset and just really got to see a surgeon. So she sent me to a surgeon I knew so little that I didn't know that I didn't have to have this man as my doctor.

I preferred women doctors, but I didn't understand that I could choose a doctor. So they got in this conversation. He was a person who specialized in lumpectomy.

And so he didn't do a biopsy. He said to me, If you have cancer, we'll just get rid of it. We'll do a lumpectomy. You'll be fine. Nurse comes in and she says, Oh, your insurance company approved it.

Early cancer experience and choosing alternatives

Now, I thought second opinion meant your insurance company doubted you, and therefore you needed another opinion to get reimbursed. So I thought, Oh, wow.

And then I thought she said, I have an opening Monday. This was a Thursday. And I heard you have the worst cancer in the world because it's only four days before surgery.

So that was my you know And then he says to me, You have any questions? I said, No. Then you tell me everything. You know the. So anyway. So I go home Friday, I go to work Saturday, lay in bed lying to my husband.

Don't worry, everything is fine. Thinking to myself. I'm not even 45 yet. This is my last Saturday. And then Sunday night a woman called me the. And she said to me, You don't know me.

But someone told me you have breast cancer and I want you to know I'm a ten year survivor to this day, 31 years later, that goose bumps arise on my arm.

As I say that, because I felt like she saved my life because I thought, oh, yeah, I can survive too. She can do it. I certainly can. That was the beginning of survival for me.

Now, you said you mentioned I was chemically sensitive. The issue for me was if I smelled something, I would get a headache that would last three days.

I would get a rash. I would be dizzy. I couldn't function normally for a long time. No idea what it was. No one diagnosed it. It was not wasn't a real thing.

It was one of those, oh, you're hysterical women. Hey, so breast cancer. I didn't have any symptoms beyond this callous thing, so it didn't seem like as terrible as what I had gone through.

Plus two years before my poor dear uncle had developed a brain tumor. Next from lung cancer, the lungs cleared up, but he got a brain tumor and they told us it was inoperable.

He's in the hospital and I was told I was in charge for no reason at all. I'm just the go to in our family. So I was told you had to have chemo or radiation or he would die in three months.

I was like, oh my gosh, you know? So I said, okay, doctors, go ahead. So they gave him chemo and radiation and he died in three weeks. And I said to them, you know what happened here?

And they said, Well, we can't promise anything. Which leads me to one of my first really strong ideas, which is, well, not my first, but one of many, which is doctors are saying something that you're not hearing.

We're hearing we're going to cure you, of course, because that's why we're treating you and they're saying we're treating you. They actually say that, but we don't hear that.

So that was bad. And he died really quickly in pain and suffering. That was terrible. So when it came my turn two years later, I thought, you know, hesitant and chemically sensitive.

And I saw an oncologist and oncologist says as I walk in without any you no conversation, just we'll start chemo next week. I said, Doc, I have a problem.

And this doesn't matter, you know, matters to me. But you know, so I tell them all this stuff, I'm falling down on the bed. And he said in the same tone, doesn't matter.

So it mattered to me. So I left and I thought, This is just not going to fly for me. I joined a support group. There was one in New York City where me and these women were sharing stories of things that I never imagined.

I had no idea, you know? One of them, father, had breast cancer. She knew a lot, and I didn't. So learning was was great. And so but they were worried for me because I wasn't doing anything, you know, they were all on chemo, radiation.

So I said, Well, I know there must be an alternative. And I said, Oh, yeah, those men. Oh, yeah, alternative. I'm going to do that, whatever it is. Now, my close friend had become an acupuncturist, and I didn't even think of it as alternative because it was my friend Franny, you know?

But that was alternative medicine. In fact, the oncologist who I didn't stay with had said to me and literally, I've said this before and it's so true, it rings in my head.

Yoga, are you trying to kill yourself? So everything was alternative. Food was alternative. You know, exercise, yoga, anything. And it was ridiculous because it was clearly an important idea.

So I started researching and finding interesting things and I was juicing and I was taking supplements and the group I was in, everyone was sick and they were getting sicker.

They were grayish, you know, they were losing their nutrients. And you could see it on their skin tone. And so some of the very great women would say to me, what can we do?

Can we try? What can we do to taste your juice?

Building a support group and exploring integrative care

So we walk together. So we kind of started I started letting them share into what I was doing, and some of them benefited, which was really exciting and it was unknown.

We didn't have a concept of integrative oncology because it didn't exist. It was alternative or conventional anyway. So that was really interesting. I started a group, we called it the whole Health Study Group, and we would meet monthly and have speakers.

We had Ralph Moss, we had Joseph Gold, who created hydrazine sulfate, a lot of a lot of interesting speakers. We had videos from clinics in Mexico. And every week, every month, rather, some women would come in and say, My doctor told me not to take vitamins.

I really want to. And we would encourage you I would encourage that. You know, you have to live. You you. But she didn't. So she would have months. The same thing.

My doctor told me not to, but I really want to. And she couldn't get passed at home, which, you know, a lot of people scary and we didn't know anything.

So I always say, and I mean this sincerely, I stumble, bumble fumbled my way, but it didn't die, you know? But I got a lot of tumors. I kept getting tumors and I kept having surgery because I thought, you know, I'll just get rid of that.

And it wasn't fine. Eventually, I had a mastectomy on the left side because I had already had nine tumors. It was the original surgeon. Of course, I stopped going to because he, without my express or informed permission, took 18 lymph nodes.

Lymphedema. If we had a conversation, we might have avoided that. But he, you know, anyway, it doesn't matter. But it was a drag. So then they went to a woman and she was very kind, very understanding.

Whatever I wanted to do, she did. So I had three little big, two other lumpectomies, and then finally a mastectomy. But nobody told me what happened next.

You develop tumors on the chest wall. Now told them stage four, 1997, stage four down there. But then I said, no, that's me. And I told the two doctors, she told me that I don't think you're talking to me and I would push it out, you know, not talking to be there for you.

I know. I was I mean, it was lovely, but I that's how I felt. And I just went with myself, you know? But I mean, that was important to me to be me. I didn't want what everyone else got just because that's what we do.

I want, you know, particular attention. I thought I did whatever. But but, you know, it was odd because every step of the way, I felt like yesterday I needed to know the information, and now it's tomorrow.

And no one told me, so what's going on? But eventually I got the idea of the Internet and that helps. So and I am in 1998, in December, I met Dr. George Wang, Chinese herbalist.

And it was a perfect timing for me because I had the 25th tumor. I couldn't have any more surgery because the chest wall was pretty much was no more skin left.

She said, we'll have to have a plastic surgeon or I can't do that because of my chemical sensitivity. And by the way, I had the other two lumpectomies and both mastectomies, which were separated by local anesthesia because after the first surgery and the general, I was awake for six nights and, you know, the same Shakespearean line that way madness was I was close to really being insane.

So I decided, am I going to put myself through that again? So I had local. So I'm here to say that not only can you survive 25 tumors, but you can do it under local anesthesia.

Just two things. Very, very powerful because we know what anesthesia does to our immune system suppresses the natural killer cells. And they didn't even really know that, but I knew that.

And anyway, so then the one started giving me and I stopped having more tumors. And then he told me, You can stop. Ten months have gone by and I was afraid and I had an MRI because I had something to prove.

So the MRI said that I had three and a half centimeters of involvement on the chest wall. It's a lot, you know. And then at the end of the time, which I took the 14 months because I was afraid to stop, I had another MRI and this doctor reading it actually called me at home and she said, Why would you have a chest full MRI?

And I tell her the whole thing and she says, I'll call you back. And then she really pays attention. Looks the whole thing over, calls me back, nothing to be seen.

So that was it. Free of cancer in August. This was 2001 and my date with my surgeon, as many people have heard, was on September 12th, right after 911.

So what a circumstance that was really, really odd. Wow, wow, emotional. But I was going to live a lot of people tonight, but not me. Yeah. What a wonderful, wonderful story for you.

Now you and we'll we'll get we'll move forward in your second journey here. But in the meantime, you found it and the Appleseed project. So tell us a little bit about that.

Well, I had been taking notes and making summaries of our meetings of the whole health group, and I saw that I had some really good information. I had about 65 pages, so I created a website.

I mean, I knew what I was doing really, but I just did it. And luckily I didn't need programing language. We were able to uplift upload in plane. So I did that and I had 65 pages and it was all interesting stuff about alternative medicine and lifestyle.

Appleseed Project and patient advocacy

And then it became something because there weren't very many Web sites or certainly no patient websites like ours. And we used to get literally we had 13 million hits over time because we were there weren't many go tos.

We'd come up in the top four. But of course as time went by, there were more and more websites and they were paying to be up higher than. So I made it into an all volunteer group because I thought people who are doing this kind of treatment, it's all out of pocket and I don't want to be another burden on people who were doing it.

And so back then it just seemed like a great idea. Plus, I didn't need the money and so it worked out for me. My dear husband has been supporting me and then I got Social Security and he's still supporting me.

But, you know, it worked out really well. And he was you know, he was nervous and he didn't know any of the things that would come out of everything. But he went with me.

That's the code. Your wife's going to die. She does want to do this, and I'm with her, which was great. So the Web site became a real thing. And then, you know, people started volunteering with us.

So then it became a real organization, became a nonprofit in Florida. And 23, it took a month, was very simple to do. I was amazed, you know, it seemed scary, but it was easy.

So we're a nonprofit and some of my friends would give me $500 here. We wanted to go to conferences and wanted to tell other people about complementary medicine and about possibilities, because that's what I used to call it, the possibilities, you know, where something worked for somebody could work for someone else.

I don't see why not. And, and so we would go and talk to patients at conferences, talk to doctors. And I will say this,

the very few oncologists are aware that it's possible to survive without chemotherapy.

So I mean, they're legit in that they don't know that it's possible. So when they meet me, I'm an end of one, but still I'm that uniquely and you come from out of state.

So I'm a regular person and I survived. So I know it's possible. You know, it's possible. And the organization grew because people respected the idea that they could talk about things that their doctors weren't talking about and that we would give them patients based evidence based information, you know, from a much more caring perspective.

No offense that a lot of doctors are quite cold about everything and they don't want you to ask any questions. And, you know, it's it's not really fun.

I've seen many errors that have been made by the medical profession. And I think many times I'm a critic and known for that. But I ask a lot of questions of cancer meetings.

And sometimes, you know, I go up to the microphone, oh, that microphone is not working anymore. Okay. No more questions. No, no. I have respect from people because they know I really mean this and I really want to help people.

And I've been able to, which is a wonderful feeling. I used to wake up in the morning, so I've already been in Thailand this morning. Look, they wrote to me from from Bangkok.

I mean, it was astounding and really fun. And then in 27, a gentleman who ran a philanthropic group said to me, you should have a conference and you should invite Keith Black.

He's the doctor who helps my my son. I said, okay. He said, I'll help fund it. Okay. Now, which did. So I started to put together a conference and then three things happened.

She said it couldn't make it to the hotel, wanted x dollars to start out and unfortunately the philanthropist died of a heart attack. So there we were with the big bill from the hotel.

You know, all these plans and no money and a mutual friend got got to the family. Eventually we explained that we really needed the support that he offered and they came through.

So we had our first conference in 28 that a hundred people and so many speakers because I really didn't any grasp. But I think we had a lot of speakers, so we covered tons of topics, but we had the one thing that we consistently appealed to is organic food.

You come to our conference, you have the greatest food right now. For the last ten years, it's been vegan or vegetarian. In the past, we've had true free range, other kinds of things.

But we're away from that now. And actually, when you're an Alaskan native woman, you own a fishery. You told me was the only native owned fishery in Alaska, sento, salmon.

And you get to taste it for two reasons. Basically, I'm pretty much a vegan, but also people grabbed it right away. Things disappeared. But it was it was beautiful.

It was her tribute to us. And she had metastatic breast cancer and and this was really special. But now, like I said, we stick with big and vegetarian and but we try to have very interesting things.

The first year we had lost the beacon, we had a chef when she didn't want to come back because she didn't want to work in a kitchen where they worked with me.

So, you know, but we changed up every year with either a different direction or a buffet of like, let's say, Indian, Italian, Asian. You know, we try to change it up as much as possible, but the food is special.

It's comes in just for us. It's a hotel. They don't have organic food most of the time. So everything the oil, the spices, everything is special and new and fresh.

So it's very fresh food and it's unique and people really like it. And during that time period, they get like a detox because they had an actual or I can tell you how many people complained to me.

And in the bathroom you should be. It's okay. It's the right thing. And I will say yes. I had the privilege of being a speaker at one of your conferences several years ago, and it was a wonderful conference.

It was so well, the food was amazing people. It just had a very nice, warm, loving vibe. You know, the you know, I know you put your heart and soul into this.

And and it's it was just very touching for me to be a part of that. And I'm looking forward to February 2024. I'll be speaking again. So tell us a little bit about.

Very excited to have you come back. We are planning for February or 2024. It'll be our 16th conference. So the things that we insist on is that it's evidence based information presented to the audience that questions and answers.

Conference growth and evidence-based education

The question at Q&A period is always there for every speaker, that each speaker have a disclosure slide. I don't know how many of the audience have been to conferences where they show a disclosure slide so fast.

Even I am a very fast reader. Cannot keep up. So we want disclosure so that people understand. Are you being paid by various groups and is that why you're speaking about something?

Because that's important to know. I mean, all of us are influenced by all of us. It's just the way it is. It's good and bad. But we are to know that is just at ASCO, the American Society of Clinical Oncology.

And this guy who is an advisor to NCI picks up a slide in 2 seconds. But I happened to see that he had a list of like 24 pharmaceutical companies that he advised.

So of course he's advising NCI and that makes perfect sense, right? Of course that that's where they are. So another thing that has happened with us, we comment on on studies and we ask questions like where their homes evolved because if you've been in to a presentation, it's all a jolly good news.

But we know there's tons I mean, that looks like a world of cancer. You might have a drug that helps you. You might have you'll always have a drug that harms OSA.

So I always try to bring that up. And I talk to people about and I say, ask the doctor what the intention is between the two of you. What are you expecting?

What are they expecting and what can happen in a negative sense? You know, I think it's important to know stuff like that. I mean, there's so many people I know this because they've complained to me.

People will say, you know, I told the doctor I got a headache when I started. The drug doesn't matter. And they look it up because I give them the link and you know, what's the number one harm? Oh, right. It's wrong.

And it happens a lot. And either docs don't know or they don't want to get involved. And then, of course, there's a subset of patients who don't want to talk to the doctor because they might stop the treatment or they might get mad or, you know, and that's bad, too.

But luckily, we have nurses, a lot of people like the nurses. The nurses tend to be very warmer and more involved. But but I think it's important to know.

But then, you know, I've said to doctors, look, there's really a couple of kinds of patients, the ones who want to know and the ones who don't want to know.

So you can find out ahead of time which one they are. And then if they want to know like me, then you could share a lot more. They don't want to know it. It's more up your alley.

I don't tell them anything, you know. But that's true. But I mean, I know people who never looked at their pathology report. They don't care. They did whatever the doctor said, and it was fine.

And, you know, that's the way life is not mine. Right. So the other thing is I used to say I had this great idea, a clinical trial. What if the clinical trial had an arm or two with the treatment of the new treatment?

The treatment and lifestyle. So patients were encouraged to take a walk before treatment or during treatment or after treatment or however it could work out, or they were offered actual food as opposed to most waiting rooms or junk food in the room.

I have seen it with my own eyes. Just the donuts. The sugars? Yeah. The Salisbury. Ridiculous. So I said to in meetings, how about if we have this a new pharmacist meeting and we can't happen.

And I mean that was the end of the Cambodian something else to say that they can patent it. It's done. So I always say to the advocate groups, why do we accept this is about us back then?

But of course it's about you know, and that's a problem because. Million dollar machine. Because it's not about sure it's not accurate about treatment.

You can see that diabetes very clearly you take your meds for diabetes and your disease progresses until, you know, bad stuff happens. It's bad. And that's just the most obvious one.

But all of them, it's a problem. And with cancer, you know, it's it's really, really serious. And we need we need that now is getting better because more and more people have heard of integrative oncology.

However, you still have to ask, do you have a nutritionist you can direct me to? Is that covered by insurance? You know, should it be? Absolutely not a question.

But in my 31 years for being the cancer world that I've yet it is a few companies that cover gym membership not really nutrition, but that has to come.

It's absurd that you go into this in this day and age and even in the Exxon, which has quite a decent, integrative program, you have to ask you have to be referred. It's crazy.

It should be side by side, like in China, where you go in the Western Hospital, you go to the herbal hospital, you just walk down the road and do that.

We should have that actually working. You should walk. Yeah, exactly. Exactly. So so tell us what happened in January 2019. Yeah. So I had a lump in the left groin and I completely did nothing.

I just looked at it. I know this is ridiculous. Why am I having it? Why? You know what's going on? But I didn't really explore it. And then eventually I said, You know what? Something's actually going on.

So ironically, it was the exact day, January 7th, that I had the first breast cancer visit. So that was pretty odd. And then they told me I had follicular lymphoma.

Second cancer journey with follicular lymphoma

Now follicular lymphoma, it's a non Hodgkin's lymphoma, blood cancer. And related to chemical sensitivity, I almost

could have guessed that I would get it, but it never occurred to me.

I'm just completely never thought with my healthy lifestyle that I could get another cancer. But, you know, stuff happens and it happens over a long period of time.

So even though the property I live on now in the community is not sprayed with chemicals or pesticides, herbicides, any of that, and I have very filtered water.

I eat organic, blah, blah, but everywhere around me, like everywhere around all of us is pesticides and herbicides, chemicals, food, additives, all that stuff.

And so it was a shock, but, you know, so I mean, this January, so then I treated it with alternative treatments that I knew. And, you know, people have told me over the years, this work great, this work, it didn't work for me.

So I have a theory I've always said, which is some things work some of the time for some of the people. So I had found my some things that might work.

Eventually I went back to the clinic in Mexico that I've been to a couple of times before for breast cancer years ago. So I had done Coley's toxins, which when I had breast cancer, had no impact.

But I took a photo of the tumor before that first needle and afterwards, and it actually shrunk in half. And then a four hour period where I had a very, very, very strong reaction.

I did oxygen nurse had to sit with me for an hour. You know, it was it was heavy duty. I was I estimate, the only person who had oxygen every time I got the nurse there, every time I had a very strong reaction.

So the tumor was reducing. That was great. But I lost a lot of weight in a two week period and I felt very frail. I was trying to walk up the stairs. It's harder and harder and harder.

But time I went home, I felt frail and I had to get back to exercise when I came home. So I started my pro program all over again from the beginning, and that's okay.

You start slow, you build back up. And I was able to do that, but it took some time. And then I got a whole bunch of tumors there, or my throat and my groin and my abdomen, you know, and I feel like I mean, I didn't really need to scan on my own skin.

And I know when something's wrong. And one of my services that you always know, even two weeks before the scan or two weeks after, so that I knew. So I had the scan and then I went to the metallurgist and this is pretty bizarre.

So the hematologist say to her, Look, I'm chemically sensitive. I'm willing to try not chemo, I'll try the monoclonal antibodies. I looked it up before I went to her.

Thank you. And genetics. And so I said, I want a half dose to start. She says, okay, we could do that. So I didn't know they do a hundred of the drugs when they would do Benadryl with steroids and Tylenol.

I never even had a Tylenol in my life until then anyway. So I get there. She's on vacation, of course. I'm sitting in the chair waiting for whatever. And a male doctor comes out with three nurses and they stand around me.

Over me. And he says to me, You're going to die if you don't do the full protocol. And I said, Nope, not doing it. I made up a half protocol and that's what I did. You're going to die.

So I stood up and I said, Well, if I'm going to die, I'd rather be home. So I went home Because I don't care. No one speaks to me like that. nobody. I won't accept it. So I went home.

I was angry, you know. But we're going to do so. Then I got a call from my doctor's nurse and she said, Come back, we'll give you the protocol and you asked for it.

So I went back and I had the treatment. I had Dr. Wong's herbs to go along with that treatment because I already knew what the treatment was and I was able to show him the potential harms, the potential help, and so I would feel protected.

I took the herbs with me. I had, you know, a bunch of calming things along with it, and it went fine and it actually was very impactful. And the tumors started to reduce and they all went away for about three or four months, four months, five months, you know, and the doctor used to say to me when I saw her, you know, you're not in remission.

And I would say, listen, here's our conversation.

Mindset, joy, and closing advice

Hi, and you're looking great. How are you feeling? So eventually she got that message, took her a while. So now the last time I saw a second. You do great.

Keep doing whatever you're doing. You know, good years. And I'm through my lifestyle and up here, I'm staying myself. I'm just living my best life, period.

And that is what I do. I'm alive now. I'm enjoying it. I mean, it's, you know, it's yeah, it's part of the philosophy of life. And I know you share it. Yes.

And so on that note, we can do a lot of physical things for our healing, right? The food, the lifestyle, the supplements, all of those things. But there's one thing that is very most important.

I put it at the top of my list is that mindset. And I know one thing that you really talk about a lot is maintaining joy in your life. So why is that so important to healing?

Well, if you worry about how things are going to go, you lost your day. So every day there's something that to be wonderful. You know, sometimes you open a social media thing and there's a laughing baby.

That's my favorite thing. Or beautiful flowers. I'm not an animal person, but I love babies, I love flowers. I like to like to experience that. And I often tell people, don't waste today because that's what you got.

There's no guarantee. None. I mean, now 75 years old. So over time, I mean, people just died. Other things, I mean, the first time that happened, it was shocking.

But somebody died without cancer. Who ever heard of that? But that's the reality. So while we're alive, we focus on life and the joy of life. It's everywhere. It's everywhere.

And it's available to anybody and it's free. That is so amazing. You do not look 75. You look half of that. And that's a wonderful getting great. Well, yeah, look at those right.

That's the wisdom that's coming out. Yeah. Well, Ann, thank you so much. This has been so inspirational. And if you were to share one message of hope and words of wisdom for women that are on a journey with breast cancer right now, what would you tell them?

I ask a lot of questions. Find a support group. Don't be afraid to look stuff up. Don't be afraid to ask questions and find a joy every day. That's beautiful.

Thank you so much for taking the time to be with us. My pleasure. Thank you.