



## Coping w/ Toxicity of Chemo During Breast Cancer Treatment w/ Dr. Hope Rugo

Dr. Hope Rugo of UCSF and non-practicing oncologist and breast cancer survivor Dr.

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Elaine Schattner discuss many side effects of chemotherapy during breast cancer treatment ranging from nail infections, hair loss and hyperpigmentation to chemo induced pain, peripheral neuropathy, chemo fog, attention deficit disorder and sexual health issues.

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### Full Transcript:

**Priya Menon :** Hello everyone and welcome to the Cure Panel Talk Show. I am Priya Menon, Scientific Media Editor at CureTalk/Cure Panel joining you from India. This is Cure Panel's 48th episode and this is our breast cancer talk series. We have featured Dr. Julie Gralow, Dr. Deanna Attai, and Dr. Jovita Oruwari in our talk series. In our previous episode we discussed triple negative and inflammatory breast cancer with Dr. Oruwari. Today's topic of discussion is Coping with Toxicity of Chemotherapy During Breast Cancer Treatment. Chemotherapy drugs are cytotoxic. They work systemically by killing cancer cells throughout the body. Unfortunately, they also kill normal cells, and this accounts for many of their side effects. To discuss and help us understand how to cope with these is Dr. Hope Rugo. Dr. Hope Rugo is a hematologist and oncologist specializing in breast cancer treatment. Rugo joined the UCSF Carol Franc Buck Breast Care Center after a decade at UCSF Medical Center working in the area of malignant hematology and bone marrow transplantation for a variety of diseases, including breast cancer. Welcome to the show Dr. Rugo. Supporting Dr. Hugo on the panel is Dr. Elaine Schattner, Dr. Elaine Schattner is a medical educator, non-practicing oncologist and a breast cancer survivor. She is a Clinical Associate Professor of Medicine at Weill Cornell Medical College in New York. She graduated from Yale College and the New York University School of Medicine. Elaine's current interests include medical ethics, cancer screening and informed treatment decisions. She is writing a book on changing public perception about cancer. Welcome Dr. Schattner.

My co-host for the day is breast cancer survivor, Beverly McKee. Beverly is an author, blogger and inspirational speaker. She combines her clinical skills and personal experience with breast cancer to deliver a message of HOPE, support and inspiration to her worldwide following through social media and speaking engagements.

I will now hand over to Beverly to begin with our expert session.



**Beverly McKee :** Thank you Priya I appreciate everybody for being here, Dr.Rugo and Dr.Schattner. Dr.Rugo can you just break it down about how chemo works to kill the breast cancer cells just so we can have a basic understanding before we talk about the side effects and toxicity.

**Dr. Hope Rugo :** Sure that's a great idea actually to talk about the work how are the works. I think there is a lot of confusion even about why people need chemo particularly for only stage breast cancer. Thinking about how they work, we have two different reasons we give chemotherapy, really 3 I guess. No 1. is we give chemotherapy before primary surgery for breast cancer, sometimes for bigger cancers and now increasingly popular to understand how new therapies work better than the old therapies or not, so called Neoadjuvant chemotherapy. That is one situation. We also give chemotherapy the most common situation the adjuvant therapy- after patient has had primary surgery for breast cancer so that no cancer you can see any where which confine to the breast and lymph nodes. We gave the chemotherapy how to cure cancer cells that are sort of hidden in places – I often refer to them as the scouts. So, breast is very vascular for the blood supply and lymph vessels have to make milk. So it's an interesting organ and what that means is that if a cancer develops, those cells can get into the blood and lymph system, and these cell can hang out somewhere else, we can see them. They are just a cell here or there and we know that they must be the reason why cancer sometimes come back later in other organs and that's the reason why people die of cancer. So we give chemotherapy for early stage invisible breast cancer to prevent cells from be able to survive and some day be responsible for recurrence. And then the last thing is the treatment we give for metastatic or advanced breast cancer where we are not going to cure the patients of the cancer but we can help women to live longer and have better quality of life by shrinking the cancer. Sometime cancer shrinks for a long long time and keep it controlled, the other times it is for a relatively shorter time. So those are all the different reasons we give chemo and a lot of times it comes out how to select what chemo 2 give. And really what we want is to understand what makes the cancer grow and then kill that. Well that's the whole concept behind the personalized medicine but we are not so great at it yet. But we to know that if we have chosen to give chemotherapy for whatever stage of breast cancer what type of breast cancer that you have, what we are doing with a chemotherapy is killing rapidly dividing cells by preying on the very thing that makes a cancer grow. So the very thing that makes the cancer grow is an inability to escape the normal signals in our body that prevent and prevent also moving around. These cancer drugs work in a number of different ways – 2 big ways – is by blocking the proteins that help with the cell division. Cells divide in order to multiply and grow around. What chemotherapy does is that it prevents the structure or the frame that the cell needs to divide into 2.

Another main way that chemotherapy works is by damaging the ability of the cancer cells to reproduce itself by getting into the way of the DNA that is specific to the cancer cells. So, it has to make a new one of itself by reproducing its DNA or by making protein through other genetic parts called RNA, and it gets in the way of that and it prevents that from happening and causes cell death. So, you can imagine that it is kind of non-specific and that is one of the biggest issue with chemotherapy. But it's amazing how it works because it does target the rapidly dividing cells, and most of our are not rapidly dividing.

**Beverly McKee :** That is a great explanation for all of us. Thank you, doctor Rugo. Doctor Schattner I have a question for you – How long typically would we expect to see the side effects from chemo, that is effecting all of our body including the cancer cells. How long generally does it take that chemo to get out of our body, and for the side effects two generally go away.

**Dr. Elaine Schattner :** That's a great question and challenging one. I think it depends a lot. First not all chemotherapy is the same. As doctor Rugo just pointed out that drugs work in different ways and they are left for varying amounts of time, some kind of toxicity like low blood count, which is one of the best studied side effects of chemo, tends to be transient, and those doctors know and usually can predict will not come back within a few days or weeks typically. Hair loss usually is a matter of few weeks but can be longer. Things like neuropathy – another toxicity – vary a lot. Sometimes problems are not reversible. You know really depends on the drug and what kind of problem we are talking about. I think you have to ask your



doctor about the particular drug that you are getting.

**Dr. Hope Rugo :** I think I just want to pop in a tiny little bit in there. What is so interesting as a physician in oncology is that when we see for example – when you know the blood count is going to drop at this time from test and recover at this time – it has everything to do with the way the cells grow. When your hair falls out, if you get nerve damage, it all has to do how rapidly those cells are growing and how rapidly they reproduce themselves. But of course on top of that, you know no matter what we think, and what we know, every body is an individual, and sometimes we see something that does not fit into the pattern.

**Beverly McKee :** I think what you say is very much true, and I was thinking this morning about the side effects that I experience as a patient, when I had a chemotherapy. Some of the things I did not know what is ample hair loss. Everyone knows that some chemotherapies cause hair loss, but I could not appreciate the extent to which hair can come back differently. Doctors did not talk about it then. Now maybe better education of oncologists, doctors are more aware of that. Some people have curly hair after having straight hair or change in hair colour. I think also, all this things that people have, may affect the speed at which they recover from chemotherapy and also the toxicity to which they are prone. For example if someone has diabetes they may be more likely to get a new vascular disease and other problems. If someone is on the heavy side, some drugs may last longer in their bodies and have more effects. Some people get cardiac effects, you know those too depending on what other illnesses, how old they are and other things and genetic factors that we may not know about.

**Dr. Hope Rugo :** Absolutely and genetic factors are very very interesting area and we know very little about, something we refer to a whole field called Pharmacogenomics. Yesterday I was explaining a patient we all have our set of genes – and everybody starts pretty much the same one – unless you get a funny one like a mutation. But what happens is within each gene, particularly the metabolism genes – there might be different forms of that gene – like some people have brown hair, some have curly hair, thin hair, thick hair – its the same kind of thing – so that that can affect your metabolism of drugs and your toxicity, and what is interesting is that we know so little about that. There are huge national and international projects going on trying to understand it better. And for some drugs the where the metabolism is very simple we do understand, interestingly in breast cancer we really don't. And we don't have tests that we use to predict metabolism. And then the comorbidity question is really important. We refer to comorbidities as other disease you might have that could affect how you do with a treatment and how you tolerate it. And of course when we talk about tolerating, we are talking about how much side effects you have and toxicity. We have for example, absolutely no understanding of why some people's hair grows in different ways, but for low white blood cell counts, we have a little bit better idea of who is at higher risk – you know if you are older we give high dose chemotherapy etc. If you have diabetes most of those patients already have some damage to their nerves, so the damaged nerves seem to be much more sensitive to damage from chemotherapy. So, but there are also many things we don't understand very well which affected as well. The hair thing is quite interesting because we use to always tell people, at least I did anyway, too bad they didn't tell you, but ..

It is an interesting thing there because chemotherapy has changed over 20-30 years. And we gave like a lot of brilliant intense chemotherapy and we didn't use the supportive care mechanism that we have now which are sure to keep your white blood cells counts, and so call myeloid growth factors our new pitch and people know it as our new lab test. And we gave higher doses of chemo we saw a lot of that hair growing back curly. Now that we give less chemo in a relatively less intensive treatment and we are able to support better, we don't see it as much anymore. That having being said there are chemotherapy regimens that particular one kind and one chemotherapy drug that in some women can cause very poor hair regrowth. That's a very nasty long-term side effect. But it definitely exists. I just saw a woman who actually had a bone marrow transplant so that's a lot of chemo you know, for leukemia. That was 18 years ago and now she has a little breast cancer, she needs chemotherapy again. Her hair never grew back after the bone marrow transplant. I was thinking about how we occasionally see that with more intensive toxic containing chemotherapy regimen. You know it's so hard to predict. We are using a lot of, you know to try and prevent hair loss so, that maybe less of an issue in a long term.



**Dr. Elaine Schattner :** Sure, well I think that your comments raised some valuable points. I think one of those is that, you know as much as each patient different from a medical perspective, person also have different priorities and values, and I think one thing that any patient with any kind of cancer can do to help themselves to avoid that they don't want – is to be honest with their doctors about the things that they most want to avoid. So when I was practicing I knew some women for example who didn't want to take any sort of anti-estrogen therapy, and others whose greatest fear was hair loss, and others who wanted the strongest therapy possible. You know people have different fears and priorities, and I think it's a good idea, before you start your treatment, to sort of think about those things carefully, and you know your doctor can not know for sure, you know how much toxicity you will experience. But being honest about your priorities will help you to find a regimen that's best for you, because, for many conditions including early stage breast cancer, there are some choices the doctor might make, like those in timing of chemo, and in which kinds of chemotherapy to give.

**Dr. Hope Rugo :** Yes, I think that's right and you know we are always talking about risk vs benefit analysis, and you know sometimes, there is a situation where you cannot avoid chemotherapy that has effects, that you would like to avoid as a person, is because if you have cancer which really responds the best to that treatment. But there are other times when you are really balancing the risk and the benefits of the treatment, so you wanna say how much benefit am I going to get, what are the short long term side effect chances, what are the ones that are guaranteed, what is the worst to me. So, that I think can drive these decisions that we are talking about.

**Dr. Elaine Schattner :** We used to use developing relationship with your doctor and your doctor's team. I think being honest is really important and I have seen patients who either felt pressure to be a good patient, or perhaps from family members or from a boss to be tough to get better as soon as possible to get the next dose, so they did not complain, and sometimes early science of toxicity, you may not want to mention them. And it could be that the drug should be switched or dose should be switched. And so one way of coping with toxicity or avoiding long term, you know, and potentially reversible effects is by being sure to mention things, and not being afraid to say what you are experiencing. I think that help and you know part of the reason that doctors have known for so long about the look like counts and hair loss in chemotherapy is that they were always measuring the blood count and hair loss, is sort of obvious. Other effects can be subtle and you may experience as a patient, not even know that they are side effects, and as much as it takes time, you know, you may feel like a wimp, that's not the important thing. Its better to be up front and to let someone know if you are feeling something new.

**Dr. Hope Rugo :** Absolutely. You know, one of the things that we tell people is to bring in a little list of the side effects you had and when you had them, because you know, you might say you had some tingling, when did that happen, how bad was it, when did it go away...and you are like O my god, you know its been three weeks since I saw you, and I had a lot going on in between, and I don't remember which day I threw up or why or what medicine I took. So I tell people that, you know really write the stuff down, call us on the day it happened...you know..a lot of times we have people send their pictures of their rash and all, because you could do that, you know, its really really helpful. So I totally agree, communication is the key. You just have to be with your physician of course and the health care team.

**Dr. Elaine Schattner :** Yes, especially now with covering doctors and nurse practitioners, I think the important thing is communication and openness about what is going on. Another thing I was thinking is, a doctor once told me, it has to do with surgical procedure, he said listen to your body, and you know, if you see to push yourself through chemo because you want to move on with your life and you want to put it behind you, and sometimes you need to rest and some of the side effects can be reduced, for example fatigue, which is the medical term for being tired, that's a very common side effect of chemo and most kinds of cancer treatment. Lot of people are tired and that may be some of chemotherapy, but could also be because the person is not getting proper sleep, or if you are trying to work while getting chemo, as I did and many people need to do. If you have children and you need to take them to school, or care taking, you know whatever it is that you have to do, it may be physically taxing. You may need more rest. Almost everyone getting chemo needs more rest than usual. So, there are things that have little to do with the cancer or



chemo that you can do to either lessen what might be side effects or just to feel better during the treatment and that would make the experience better and may in fact improve the outcome overall. You can not protect thoroughly against side effects necessarily, but you know getting sleep, avoiding exposure, or certain kind of things can be helpful and you know sort of increase your chances of getting through without any big problems.

**Beverly McKee** : Well, Thank you Dr. Rugo and Dr. Schattner for insight and great advice. I know we have panelists who are eager to ask their questions and Priya is going to introduce them for us. Priya?

**Priya Menon** : Thank you Beverly. Panelists we have today are Nicole. Nicole Chryssicas is a Senior Writer and Public Relations specialist for a large regional hospital system in the Boston area and author. She creatively shares her physical and emotional experience throughout her cancer journey in the hope of touching other lives affected by this disease on her blog, [seaglassinthemidst.com](http://seaglassinthemidst.com).

We also have with us Jennifer Lloyd. Jennifer is an EMMC foundation philanthropy officer with primary responsibility for EMMC Champion -the cure challenge oncology support project and emerging community fundraising priority. She has secured more than 1 million dollars for cancer research. Jenny is a breast cancer survivor and often volunteers at times for regional advancement efforts through her church and through her radio broadcast in hope to boost faith in their own cancer journey.

We also have with us, Shweta Mishra, joining us from India. Shweta is a biochemist and nutritionist. She is also a science writer and blogger. She aims to provide best practical nutrition counseling and education to cancer patients to help improve their quality of life.

I welcome the panel today to the show.

Before we begin with our panelist session I would like to remind our audience that we will be taking in questions at the end of the discussion. If you have a question for our experts and panel, please press 1 on your keypad and we will bring you live on air to ask your question. You can also mail me [priya@trialx.com](mailto:priya@trialx.com) with your question and we will get them answered.

Beverly...you can start with the panel discussion.

**Beverly McKee** : Thanks Priya, Nicole do you have a question for the experts.

**Nicole Chryssicas** : Absolutely, thank you so much for having me. It is a great topic. Personally over the course of the cancer journey, I think, greatest challenge is to map out expectations when you're in the throes of a given treatment, specifically chemotherapy. Few things that I thought about in the course of going through chemo – one of the things -Though it's been 10 months since completing Taxol/AC, there are so many uncomfortable side-effects including neuropathy during treatment, but my nails (both finger and toe) seem to take the hit hardest even post-treatment. So, I had an infection in which fluid oozes out of my nails – its nasty with some even lifting off completely. So, though the infection and oozing is finally passed, I still have some discoloration and nail lift that I was hoping would have subsided by now. Can I expect them ever to be normal again, and will the ridges ever completely go away?

**Beverly McKee** : That's a great question Nicole. Dr. Rugo can you answer that for us?

**Dr. Hope Rugo** : That was a great question and also your interest in this work is pretty exciting. I appreciate that very much. The nail thing is one of those funny things. You know we are always telling patients about fever, and hair falling out, and talk about time frame and that kind of thing, but some of the things are not life threatening but are incredibly irritating, are not mentioned at all. One of them probably, the most distressing one is these fingernail things. It seems to be mostly caused by the Taxane...but see it really when a patient





gets a CT, so it could be Cytotoxin followed by Taxane, It could be Taxol or Taxotera. Sometime we see it when you don't get the A part at all, you just get the Cytoxin and Taxotera – so called TC regimen – and what you see is exactly what you got. Sometimes you see a dark half moon as the finger nail is growing out and then you see this diving line – It's their tree line where their chemo stopped their finger nails from growing and then the new nail grows out under the old nail and the old nail lifts up – and that little dark space is just a space for bacteria to grow. The bacteria that are part of our skin – just regular you know so called flora. So this is a very common – and sometimes it occurs after you finished your chemo – so you are kind of caught unaware, just like I had patients whose eyebrows fell out three weeks after the last chemo. The nails completely recover, but the unfortunate thing is – the nails like to grow kind of slowly during recovery process, so generally if you have that in most of your fingernails – you have gotten Taxotera as your taxane, but not always. And it takes three months or so and then it goes away. Now the fingernails that come in may still be somewhat affected by the chemo you got so the new nails may be little bit thinner and likely to have that vertical slit. But they do eventually heal and go away. That's in contrast to my patient who had a bone marrow transplant who still has funny nails – growing as thin flat ridgy nails now at 18 years after transplant, because that chemo is really big – a kills all type chemo. Now, one thing I do tell patients is when they start having their finger nails lifting off or feeling sore – like first it should have happened to you too – first your nails feel sore while they are still intact -I tell people to soak their nails in warm water, sometimes warm water with tiniest bit of salt in it – should not be salty water, but just a tiniest bit – that is how they clean out with underneath the nail – to prevent it from getting yucky. And then if they get that – sometimes it may be smelly actually – they have this stuff coming out of their nails – so it's kind of like of looking at a space alien, so I tell people to soak their nails again, but then e usually give antibiotics that treats the bugs that grow – it makes it go away really really fast and it gets better. I really see these problems, occasionally people who have been on chemo for along time, who have advanced breast cancer – can get have ingrown nails something like that, but that is uncommon in this early stage type treatment.

**Nicole Chryssicas** : Ok..that is great thank you so much.

**Dr. Hope Rugo** : one little last thing, I wanted to tell – we don't do this but some people have found that putting their fingers in cold water is helpful. But we don't know if it is helpful because nobody have done a study on it. But, some people do put their fingers in cold water, with the idea that just like we put cooling caps to try and prevent hair loss. And, you know maybe that helps – It's hard to know, because there really hasn't been any data on it, and of course then your fingers are cold. But it is something to think about.

**Beverly McKee** : All right, well, thank you Dr. Rugo. That's a great question Nicole, because a year out of chemo I still have those ridges, so I was glad to see that you were going to ask that question. Now we are going to go to Jennifer. Jennifer I understand you are having all kinds of snow where you are and you might not be able to stay the whole show, so I wish you warmth, good weather and then your future. So, You have a question for our experts?

**Jennifer** : Yes, One of the most common thing that I hear from the women I encounter is what they are calling "Chemo fog". And the dilemma it seems to be, many of these women are also facing menopausal symptoms, so they are commonly told that their inability to remember important dates or their to do list has to do more with the hormonal changes that their body is facing and perhaps less due to the chemotherapy agents that their bodies have endured. Can you please speak to what we are now learning about chemo fog and its relevancy in the post survivorship kind of work plans for a survivor?



**Dr. Hope Rugo :** We just finished a project on that. I would certainly want my colleague to comment on it too, but I want to mention a little bit about our data.

**Dr. Elaine Schattner :** Sure, I think the problem with chemo fog or chemo brain is an area of intense research now and its something for years that doctors tend to minimize. Yes, its true that there are a lot of women who get chemotherapy for breast cancer are nearing menopause or after menopause – and then we are on that time – there is not a lot of data and information on that because its hard to measure changes in how people think. A lot of women when they are sick and tired they don't feel so well, and they don't think as clearly as usual. So, this is a scenario which is hard to measure, and that's one of the problems. Another thing is that doctors want to help people and not harm them, so for years, you know, it was sort of convenient to think that the changes that women experience during chemo were not a harm from the chemotherapy, and it turns out from some studies that some of the old drugs – such as 5FU and also drugs like Tamoxin can have changes on how mammals think. I think that key point is that it varies a lot. The effects are really subtle and usually reversible. But it could be that an older person getting chemotherapy is in general more vulnerable to changes than a younger person. Younger brains are more resilient. I think the condition – chemo brain or chemo fog is now popular now in the press, so people who are getting chemotherapy feel it more and, you know, they may by worrying seem to experience it, when it really is a reversible thing that they are tired and you know it may not be such a real phenomenon for most people. However, as I mentioned that, research in the past few years have shown that for some there are some damaging effects which doctors and researchers need to study very carefully, because you want to make sure that the drugs you are giving is worth giving and are not causing harm. I think, in general just to say, you know, because this show is supposed to be about side effects of chemo, to put this in some perspective, most people in my experience, who receive chemo do well with the chemo. It is often not as bad as people expect. You know, you get the first if side effects and it can be scary, and often people, not always – you know I don't want to give advice on a program but often people are relieved after the first dose, that it's not what they expect. You know, it's not a picnic, you know, and drugs vary if you work with your doctor. And if you report symptoms early, you need not be so afraid because you can change the dose or change the frequency or the way its given. Anyway Dr. Rugo, I think may be you should talk about the research you are doing.

**Dr. Hope Rugo :** Sure, First just to respond to the last thing you said about how you can change the dose of the chemo or whatever, it is actually not that simple. I think in the advanced stage setting where we are treating patients to help them live longer, and have good quality of life, that is an absolute possibility, and you should never be stuck with, you know doggedly continuing chemo that causes tones of side effects and severely or even moderately limits your quality of life. That should always be a discussion. But for early stage breast cancer, it is often not possible to maintain the same effectiveness against the cancer and change either the dose or the schedule. In fact, there is pretty good data that if you don't give the chemo on time or if you change the dose, that you really limit the effectiveness, so in some ways, if somebody is really having a hard time and can't get the treatment, it is better to give 3 or 4 cycles of Adriamycin and Cytosin, one of the common chemo combinations used in the past, rather than to dose reduce for the remaining cycles, because, to me, it seems like, you are getting the side effects without the same degree of benefit you are hoping for. So, I think that the way we tend to manage the side effects – first of all most adjuvant chemo or neoadjuvant chemo given to cure women of early stage breast cancer is indeed reasonably well tolerated. People get through it and I completely agree, it is the supportive care that gets people through it. It's the growth factors, the antibiotics needed to avoid the mouth sores, you know making sure you hear about any kinds of side effects that is bothering somebody. Even trying to take care of the nails and you know doing the best we can to make that as tolerable as possible, because that can be an ongoing issue, that patients are dealing with long after their chemo is done, the gifts that it keeps giving. Coming to the cognitive effect, this is something that we were interested in long time ago, and it is interesting, the whole field have changed



overtime. We used to give much more, as I mentioned earlier, 10 times of chemo for breast cancer and also we did not have the growth factors that help to keep the blood count strong. And one of the side effects of keeping away blood cell count strong is we see much less in a way of mouth sores, and general sort of badness, acute toxicity. And with that has been less of this chemo fog. That is actually a big gift. Chemo for actually came even more to light, because in the 90's we were doing bone marrow transplants for breast cancer, and people got this huge doses of chemo, and then bone marrow transplants to rescue their bone marrow back. Those patients have permanent; I mean some of them, some permanent cognitive, sort of personally assessed change. But they were really sick and in the hospital for six weeks and intensive treatment. For the kind of chemo we give now, the main...I completely agree with my colleague that, most of the side effects are modest and they resolve over time. That's what the current data suggests. And when we looked at patients – we had a study where we did imaging of the brain and we did very detail cognitive tests during the course of adjuvant hormone therapy, chemotherapy or both, and others of course have recently published or presented data on this. It is an interesting question. There is controversy about what this is due to. It's clearly if you give a treatment that is really toxic, that affects at least short term or something our sense of cognition, but lot of it, as it was mentioned, is contributed by lack of sleep depression and the acute effects of menopause. The side effects of hormone therapy, that is anti hormone therapy used to treat breast cancer, that is so critically important, and reduces the risk of occurrence of hormone sensitive breast cancers quite significantly, those drugs may also cause the symptoms. Now, is it that we all turn stupid, that is the question. That's not really what its meant. We call it cognitive dysfunction, and that sort of means that you know you are not thinking normally, or there abnormality in your thinking, but turns out that if you ask someone to add a bunch of numbers together, they are doing just fine. The issue is more with what we refer to as executive function- it is short-term memory – it's the kind of things that we notice when we age- which is that we have name finding problems – we forget people's names, we forget names of things, we forget why we walked into the room. You know you have to write a list, because you cannot multitask as well as you used to be able to. Few people note that they have trouble focusing on reading or any of those things. It is separate during the acute chemo period, which of course is due to a myriad of short-term issues, the drugs, the medications, the treatment symptoms etc. So this executive functioning is interesting, and when we looked at patients overtime, we saw that it was contributed to a lot, as others have found, by antidepressants, lack of sleep. But that depression alone is not the only thing. It turns out, the menopause issue and hormone therapy, I think, do predict some of that executive function issue. Now, what can we do about it, because, if you have breast cancer you need to take say, a hormone therapy like Tamoxifen or Remicade inhibitor, in order to have a big effect on risk of recurrence, you don't want to take it. On the other hand, you don't want to forget everybody's name, or why you walk into your room, or put your keys in the refrigerator, and trying to think of the stories you have heard and people know. So, what should you do. Well, there is actually a lot of programs now that are trying to help people with that exact function – which is brain focus – telling your brain to focus well, little mind games that you can do online, that are available for usually at cost but not for very much money and they help. People have some for example have been doing sudoku- which is not one my favorite things or crossword puzzles, which are really cheap. These are not my favorite activities, but many people have found out that they actually improve their speed of processing. So, I think that we don't have to worry too much about having permanent cognitive effects from current standard day chemotherapy for breast cancer. We may notice some short term effects, and those effects I think we can counter by relatively simple maneuvers which we need to actually need to incorporate in our daily lives anyway we age.

**Dr. Elaine Schattner :** I might say as a matter of agreement that Dr. Rugo – I extend that it's hard to change the dose of chemo, when it is given as a standard protocol, or for women where we are giving it for purpose of cure, basically, of eliminating or lessening the chances of recurrence, and I agree completely that you don't want to lower the dose without any good reason. I wanted to tell as a patient, one thing what I experienced. I was getting a regimen called AC – Adriamycin and Cytosin – as many listeners would know. But by the fourth cycle I was completely wiped out. And so much so it was hard for me to read even a magazine. I could only watch TV, and working became impossible. And I think it may be helpful for people to know that it does reverse. I was worried that it wouldn't reverse. And this sort of foggy state that can





happen, especially after several cycles of chemo, is something that usually gets better. Again it varies from patient to patient, but I think it helps to know that it gets better.

**Dr. Hope Rugo :** That's incredibly important to remember that fatigue can be profound from AC, but everybody does recover. One thing that does happen with this fatigue which – the NCCN has fatigue as one of the sort of treatment diagnosis, and, I am on the fatigue panel. I think that's really important, because a lot of physicians and care providers don't really think about it. But the good thing about fatigue in this setting in early stage disease is that it goes away. But it's interesting, as you were saying earlier, to tell patients to listen to their bodies, and of course I tell patients that- and what I say to them, is that if you are giving weekly Taxol, you can work part time. But if you are getting every 3 weeks – Adriamycin and Cytosin like you got – and we often give it every 2 weeks – so we eliminated the third week, so the time you get the chemo is shorter which is great – but we have eliminated the week in which you recover also, by using our growth factors, or these shots that keep your blood cell count strong.

So, to tell people, during AC, it is next to impossible to work much. Now if you have a little project that you can do at home, that's great, but that's so called burning the candle at both ends. And if you work during the AC, you will be really really tired at the end of it. The..and then it takes longer to recover, you know, I don't have great scientific data on that, But I have this observation that people who really really push themselves, actually take longer to recover. I actually think, may be, its a little bit more depression during the recovery period, because it's such a hard time. You know, you feel like you should be done and better, and you still don't feel great. People who get radiation after adjuvant chemo, you know we usually we wait one-six month or so before starting radiation, but if you got chemo and then if you are on radiation, you get more tired with the radiation than you would otherwise, and it takes longer to recover. So, I think that, you know my husband always says that when you die your work will still be there actually. So one of the things is to give yourselves a little break and to not work as much during that period of time because I have seen that – one – it is easier to get through, but two – that you should recover faster. One last little comment – for people who have advanced stage breast cancer sometimes fatigue is a mind numbing thing. I mean, you are just so tired, can't get things done, and it really really affects quality of life, and there is not as reasonable a chance for it to go away, because many people don't get much of a break from the chemo, because the cancer just grows. So we actually sometimes use medications, we use Riddeline – which is a drug used for attention deficit disorder in children, and it is self dose – so you take it when you need it, when you need to go out and do something, you know you can pull back really early – it can just help a little bit. There is also drugs that are used for people who do the night shift – who need to be awake all night – and those medications can help as well – although I find that these are covered less frequently by insurance. So, we actually use it in patients of advanced breast cancer, and it can be very helpful.

**Jennifer :** I was going to ask about that Riddeline Dr.Rugo, because I just read about a study that sometimes it can help with thought process and the chemo brain. It's a new study that I had seen, and I was curious about that, so great that you mentioned that.

**Dr. Hope Rugo :** Yeah, I mean I still think that the chemo brain stuff is little uncertain in terms how little it helps, but it clearly helps with the ADD, so I think, in as much as I see, sort of chemo brain effect being executive functioning, difficulty in multitasking, because you keep getting distracted by things. It's interesting, I have aged, and also have noticed that if I take a red eye to Chicago – where you are on a plane for 3.5hrs – you know, I have that in the morning, first thing if I am trying to function and give a talk at 7 in the morning. You know I think that it's very similar to that. It's almost like you are just pushing a little too hard,



so sometimes you obviously have sleep upset. Sometimes these medications just help to refocus. I think in this situation it might be worth a try if you really have a lot of symptoms. And then in sleep wake disorder – this idea of taking medication is truly worthwhile, and to talk to your physician about these if you have profound fatigue in the advanced stage setting and see whether these medications they might recommend, that could potentially help.

**Jennifer :** Great advice for all. Thank you so much. Shweta do you have a question for the experts?

**Shweta Mishra :** Thank you Priya for having me on the Panel, and Dr. Rugo, Dr. Schattner and Nicole, it was really amazing to hear you all so far. And I guess without wasting too much time I will just jump straight into my questions, because I am sure there must be many listeners who are waiting for their questions to get answered. So, my first question I guess will be about breast cancer in men. We, mostly see Breast cancer as women's disease, but how common is it in men actually, and is the etiology and treatment line same as that in women?

**Dr. Hope Rugo :** Breast cancer in men represent just 1% of all breast cancer diagnoses, so it's quite uncommon. In men of course then, it follows many of the features that we see in women, that increases with age, but it has some other specific features too. If a man is diagnosed is breast cancer, because it is uncommon, we always be considering testing for genetic mutations that increase the risk of developing cancer. And many men who have breast cancer will also have mutations in the BRCA 1 or 2 gene, and now there are additional panels that can diagnose families that have increased risk of developing breast cancer, although these are quite rare. But that might be helpful in terms of family counseling and also in terms of monitoring for these patients. You know when I see a 36 year old man with breast cancer, I would say, every single one of them I have seen has had a BRCA1 mutation. So, it's quite common. The other thing which is quite common in men, is that tumors are almost always estrogen receptor positive or hormone sensitive. For women that the most common form of breast cancer too, somewhere between 60-80% breast cancers are hormone receptor positive, meaning that they respond to anti-estrogen type treatment. In men, it is much higher than that. Almost in all men, male cancer is hormone receptor positive or hormone sensitive. So we treat now breast cancer – it is very very hard to study the male breast cancer because there aren't enough cases. But what we found based on people's series so far – is that – basically these cancers respond similarly to hormone receptor positive disease in women, and we treat them similarly. In hormone positive breast cancer we tend to give chemo, we treat almost all men with hormone therapy. The standard has been Tamoxifen, although it is clear from studies that happen to look at population with advanced breast cancer metastatic disease – that both the aromatase inhibitor and the newer sort of Tamoxin like drugs Fareston also work in men, we just use them more in the advanced stage setting.

**Shweta Mishra :** It is interesting to hear that. I guess, that answers my second question about what is most common type of breast cancer in women and what are the risk factors behind that type of cancer? I think you just mentioned that it is the hormone receptor positive cancer, right?

**Dr. Hope Rugo :** Yes, that's true, it is the most common subtype. We can talk about the risk factors also.



**Dr. Elaine Schattner :** If I may, Dr. Rugo, it was spot on. I was also thinking about the psychological effect or just having the condition in men. Some may feel uncomfortable telling people that they have breast cancer relative to women. And then in itself, it's not quite the toxicity so much, as it is the added problem, you know having to explain or either or not say what they have and what they are being treated for. That is just sort of an added burden that some men may perceive or feel that they have breast cancer and need treatment.

**Dr. Hope Rugo :** It's a great point Dr. Schattner. It is challenging for all of us but for men in particular. Really challenging, you know, and how you sit in those rooms with women. We have these psychological side effects. It is a really big issue we have not talked about yet, we can talk about it in a moment I think. And we really don't have good direction how we deal with these questions in men either, but I just wanted to – before we moved on – very briefly touch on the risk factors for developing breast cancer. Being a female is the biggest breast cancer risk. One in eight women develop breast cancer, and I think your lifetime risk is somewhere near 13% range. It is the most common cancer diagnosis in women and the most common subtype is hormone responsive. Lot of the risk factors that slightly increase your risk, I mean its not huge but just slight increase in risk are not modifiable – Like having children late or a longer exposure to estrogen, because you are going to menopause later, start your periods earlier. There are some modifiable risk factors that we can affect – are not being being very overweight, particularly not gaining a lot of weight after menopause – that seems to be a risk factor. And then, the other risk factors such as drinking alcohol regularly – more than 2 glasses of alcohol every night, those women tend to weigh more also, but there is some risk associated with drinking more and higher risk of developing breast cancer. If you have a family history, even if you don't have a mutation, you risk is increased. So you want to pay more attention. I have to say, in a clinic, which is only breast cancer, I have a tremendous number of patients, and majority of my patients have no family history and no particularly unusual risk factors, you know. Being Caucasian is a higher risk than other ethnicities, although the risk of dying of breast cancer is higher in young African-American women, because they get a nastier subtype of breast cancer. And those are having dense breasts, in California, I have to let everybody know, when they have dense breast on a mammogram, but we have no recommendations for what to do about that, which is kind of a silly thing, you know. One thing talking to another, but then for us, really a reflection of having more estrogen natively, from your body's genetics or metabolism, and having more estrogen, does seem to increase your risk. So you have dense breast and if you find a lump, you need further investigation, a negative mammogram. I should never convince you that nothing is going on, although many times you won't be when you feel something is always worth pursuing.

**Dr. Elaine Schattner :** Those are great points about risks. I just might have a thing. Sometimes when women get breast cancer diagnosis, they wonder what they can do or what they should have done. I think when I was, set to patience and tell family and friends now, in general, it is a good idea to take care of yourself, with or without breast cancer. So, we don't really know if you point out exactly what the relationship is with fat or fitness or alcohol. The data is what is called co-related – meaning they go together, but it is hard to prove cause and effect. But its a good idea for reasons of heart health and fitness to say, not to be obese, to be on the thinner side, not to drink too much, to exercise as you can. All these are just sort of good things to do, whether or not you have breast cancer, and may reduce the risk of getting it, or if you had breast cancer, for recurrence.

**Shweta Mishra :** Ok, thank you so much for that answer and you mentioned that longer exposure to estrogen is one of the risk factors. So I am just wondering, patients who are on IVF treatments, they are kept on estrogen pills for very long periods of time, like 2-3 months initially. So, does that increase the risk for having breast cancer in future?



**Dr. Hope Rugo :** It is a really good question, and one we have always been very interested in. There are a lot of patients who do IVF now and we have not seen a big increase in that population of breast cancer. Most people don't do very many cycles, due to the cost. And it does appear that short-term increase in exposure to estrogen in women who are generally premenopausal, does not seem to increase risk. I think the number of women who are post-menopausal and use IVF to have babies, its very very small. We also don't have a good read on people who do 20 cycles or something. We try occasionally to talk to people who have done such a thing and whether or not their risk is increased. In general we think of it as not increasing risk. In a woman who has already had breast cancer, that's a separate issue, and then we really are balancing the risk of recurrence and time since diagnosis and need for other types of treatment.

**Shweta Mishra :** Ok, Interesting to hear that. Should I move on to my next question, or do you want some other callers to take theirs, because I have so many questions. I don't want to steal other people's time.

**Priya Menon :** I have a question from one of our listeners; we have not really touched on. Her question is "I have peripheral neuropathy in my feet after chemo. Do you think low level laser therapy would help?"

**Dr. Hope Rugo:** There is not any data to support the use of laser therapy to treat neuropathy. We treat the peripheral neuropathy with something like – Gabapentin or Lyrica. That works pretty well. Some people find acupuncture works too well, wearing shoes that don't fit, makes the neuropathy worse. But I have not found anything else that does help. There really isn't data, I would be worried that, I don't know what good that laser therapy really is, or what data supports it, and I would be worried that it might cause other problems.

**Dr. Elaine Schattner:** I agree completely. I read a bit this morning.

**Beverly McKee :** Ok. That's good advice. We are down with just a couple of minutes. Nicole do you have one more question that you would like to talk to the doctors about?

**Nicole Chryssicas :** Sure, You know there is something I thought about regarding, you know chemo. I understand that chemotherapy can often compromise vital organs in the body. And I know that spleen not necessarily a vital organ, a recent CT scan that I had revealed several low-attenuating lesions on my spleen. Though my oncologists don't seem to be concerned about this being metastatic disease, what is the likelihood that this could be related to the toxicity of chemo? If so, will they go away overtime?

**Dr. Hope Rugo:** So, tell me you had a scan for what purpose?

**Nicole Chryssicas :** Well, this scan was actually for my reconstruction surgery that will take place in June. So, they were looking at blood vessels for a flap surgery. When they were in there, of course you don't get the best pictures of the spleen, but the Tech person did get a- notice several lesions.



**Dr. Hope Rugo :** Did you have this scan before?

**Nicole Chryssicas :** I was scanned a year prior and there was nothing there, but again, there is a question that may be the radiologist did not take notice, because may be it was just something..you know

**Dr. Hope Rugo:** I would say that, one of the biggest challenges we have with these scans is that they show all these things that are meaningless. You can have cysts in your spleen and all sorts of things, little islands that show up. The biggest problem we see is not actually the spleen but the little nodules in the lung. You know we see it all the time, these people must have had bronchitis when they were younger, that did not really manifest itself as something they worried about, or may be they did, and took antibiotics for really bad bronchitis, and then you end up with these tiny lung nodules – they are just scars. And so, you know, often time one scan will beget lots of other scans which is an unfortunate thing and even sometimes aggressive treatment. I agree that if you see non-specific findings in the spleen, it is most likely something very benign. Sometimes for example, I had a patient who had a scan for another purpose, questioned a liver lesion. She is at high risk of recurrence, so there is huge anxiety, you can imagine sleepless nights. Anyways, thanks for were able to get a PET-CT done very quickly, and we didn't see anything. So, in this situation what we generally do is follow up with the PET-CT scan in three months or something. The advantage of the PET-CT scan is that those little things – if there are anything to worry about they will pick up the radio-labelled sugar that used in a PET scan. But my guess is that these are not anything, but something you had all your life, but just did not show up in earlier scans.

**Nicole Chryssicas :** That's very reassuring. Thank you.

**Beverly McKee :** That's great to hear, I am sure Nicole. It is always frightening to get anything on the scans.

**Dr. Hope Rugo :** Well, That's the problem with the scans. In fact, our guidelines recommend that you do not do, you have to do it for this purpose, those for your flap, but I still see people getting yearly scans, and lot of radiation for no benefit.

**Dr. Elaine Schattner :** I think the " choosing wisely campaign" does not recommend routine scans.

**Dr. Hope Rugo :** That's right, actually there is nothing they recommend for routine scans. No guidelines. Then we have very low threshold for scanning, because there is no point in waiting. I would never recommend someone to come back at 3 months if they are having pain or symptoms. Why should you be worried about it? We merely know what's going on.





**Beverly McKee** : That makes a lot of sense. we covered so many of the questions that our listeners have asked, but we do have one that we have not touched upon. And for our listeners I am a cancer survivor dealing with sexual health issues. Who can I speak to about this for help ?

**Dr. Hope Rugo** : It is a really big issue, just a huge one. You know of all the toxicity things we talked about that we can't fix. but we can certainly intervene, like in neuropathy, for example, we have something which can help, but can't make it go away. With sexual dysfunction in women, someone is having to do that greatest job of helping, I mean I think that's the thing. What's really important is to be able to talk about it to see if there is anything we can change, or you are on a medication that's worsening the sexual dysfunction, that you can spare. You can't spare the hormone therapy due to breast cancer, but you can spare may be something else, you know, how important is it that you put me in menopause in my treatment with monthly injections? Because that's going to affect things as well. So, these things are important to talk about. I take the approach, I think for women, sexual dysfunction is different obviously than in men, because they have to just get some blood flow in there. For women, its not just blood flow, there is a lot of issue with libido and not having orgasm, and all sorts of things. then you get this dryness, sexual intercourse hurts, and then they don't have may be have breast and nipples that will help with that sort of libido issue, and so it's a really complicated situation. So, we actually work closely with our OBGYN, and that helped a lot. We work specifically on vaginal dryness to use the estrogen ring or Vagofam, and monitor blood levels of estrogen in women who have a lot of vaginal dryness , because, there is nothing like having horrible dryness and tearing to make sex no fun. The other issue, I think is – sometimes actually these anti- depressants which previously may have been thought to reduce libido and prevent orgasm, may actually in the long term – some of them may help with libido and restore sensation to some degree, and blood flow. So, that's something to talk to your doctor. Then I think, more sort of preparation is important. And having a partner who is very willing to work with you on that, that makes a big big difference for women, and increasingly so with treatment with breast cancer and with menopause even without breast cancer.

**Dr. Elaine Schattner** : I know we are running short on time. I might say that I think this area of sexual health during and after breast cancer treatment is an area of needed research. It is sort of something which doctors did not used to talk about or ask about. We are learning that there are these effects, as Dr. Rugo says, having a partner who is willing to work with you is helpful. Finding a healthcare provider, be it an oncologist or the nurse. You know oncologists might not have time to deal with the nitty gritty of things. Sometimes, simple things like lubricants can be helpful. But you need to – you know and also peer patients may be a resource on this.

**Dr. Hope Rugo** : Absolutely,very very important.

**Dr. Elaine Schattner** : But I really think, it's an area that research is needed to address.

**Beverly McKee** : Absolutely, You know I just wrote a blog on that, not long ago, and the response from people all over the world, was unbelievable, because we don't talk about it really that much. And people are having this problem, it is embarrassing. They are thankful to be alive, and now this big problem, that they don't want to bring it up to their doctors necessarily. So, I think it is definitely something that we should keep discussing.



**Dr. Elaine Schattner :** And a lot of doctors, there is a paper out today about aging of oncologists – a lot of doctors are just not comfortable talking about it, even if they feel they ought to.

**Dr. Hope Rugo :** That is why you have these allied health professionals. So, you know if you happen to be somebody who does not feel comfortable talking about sex. I think that one of the things, that you can do is – I mean there is a number of different things to ask or even recommended is – you send that questionnaires to people so that you can focus on what questions they have when they come in. So, that's one thing that can be helpful. The other thing is – meet with the nurse in the clinic, or somebody who might be able to ..and else physicians. you know we need to also, work with our allied health professionals to make sure that these questions can be addressed, when physicians may not be the ideal person to talk about, depends on patient and physician comfort.

**Beverly McKee :** great advice, absolutely. and we actually have gone over and hour, and we all have just been chatting about all this incredible information. Dr. Rugo, do you have any last talk that you want to share with the listeners.

**Dr. Hope Rugo :** I think that breast cancer is unique, in that it is so common and so curable, but also that basically cure is associated in most cases with treatment that has some noxious side effects. With open communication with your healthcare team and with an understanding of how we can reduce side effects, and then treat them, understanding the time course of these side effects. Most of this therapy is very doable and you go back to your normal life after its eventually – without – I tell people it's a year – to recover form the fatigue, you nails, your hair. But then you recover from it. This open communication and ability to be able to talk about the issue and manage them perspectivaly is very important.

**Beverly McKee :** That's great information and great advice Dr. Schattner, do you have any last thoughts?

**Dr. Elaine Schattner :** I agree completely about the open communication and partnership between a patient and doctor, helping through any kind of cancer treatment. Also, just to say, thank you for helping me for including me in the conversation and for helping women who have this condition, giving them more information is important work, I appreciate being included in the conversation. It's great to have you, and I thank everybody who is involved, because it seems like everybody is really doing tremendous work in breast cancer.

**Beverly McKee :** Thanks to both of you, and thanks to you Nicole and Shweta, and Jennifer. Priya is going to come back on the line to wrap us up today.

**Priya Menon :** It's been a such a wonderful discussion and I have been listening and learning a lot. Dr. Rugo, thank you very much for being with us today, I know you are very busy. Dr. Schattner it was great to



have you with us today. Beverly, as usual you have been great, you are doing so much good work for the breast cancer community. Nicole, Shweta and Jennifer...your participation enriched the conversation.

I thank the audience for their support. For our upcoming shows on breast cancer please visit [curepanel.carefeed.in](http://curepanel.carefeed.in) You can always mail me [priya@trialx.com](mailto:priya@trialx.com).

Our next panel discussion is on prostate cancer on 19th March @ 6pm ET and we are discussing Active Surveillance in Prostate Cancer with Dr. Laurence Klotz of Sunnybrook Health Center, Toronto.

Thank you ladies for being with us today.

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