



Sexuality and Lung Cancer Patient Panel

Thank you so much for joining us for the Caring Ambassadors Program video series, Learn from the Experts. Our main goal is to empower and educate patients and communities to be advocates for their health and to improve their lives.

Today's video is dedicated to living with lung cancer and it highlights one chapter from our book, Lung Cancer Choices. The video series is broken down into short segments, so it's easy to watch and navigate. You can watch the videos in any order, so feel free to choose what interests you the most.

I'm Lorren Sandt, the Executive Director at Caring Ambassadors Program, and I'm joined today by Cindy Langhorne-Hatfield, our Lung Cancer Program Director, and a panel of people living with lung cancer and caregiver(s). We're very excited to welcome Dr. Loise Wairiri, as our featured author in this video. Loise will be discussing her chapter, Sexuality and Lung Cancer.

Dr. Wairiri grew up in Kiambu, Kenya. She earned her medical degree from the University of Nairobi, College of Health Sciences, and thereafter worked in rural health where she developed interests in breast and cervical cancer in resource limited populations. Her clinical interests include medical education, promoting health/cancer literacy in communities, and health equity in cancer care. Loise is currently a resident at the University of Washington, Department of Radiation Oncology, in Seattle, WA.

Sexuality-related concerns such as sexual health, intimacy, reproductive health, and gender are prevalent among cancer patients from diagnosis, during treatment, and can even extend years after primary management. In this video, we will discuss sexuality concerns, mechanisms, how they relate to cancer, and interventions.

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We hope that this video will provide helpful insights and information for patients and caregivers dealing with lung cancer. If you're interested in learning more about the Caring Ambassadors Program and our mission to help patients with lung cancer, please watch the video series.

And please share this information with anyone who might find it useful. Together, we can make a difference in the lives of those affected by lung cancer.

Sexuality-related concerns such as sexual health, intimacy, reproductive health, and gender are prevalent among cancer patients from diagnosis, during treatment, and can even extend years after primary management. In this video, our panel will be asking Loise the questions they face as patients and caregivers.

[Sherry] I've been on cancer treatments now for 5 years and I'm menopausal, and dryness is really a problem during sex. I don't know if over-the-counter lubricants are the best or if I should be using something else?

[Loise] Thanks Sherry for your question. So, this is really a two-part question I would say certainly cancer treatments have been known to cause vaginal dryness by affecting the levels of estrogen, however, also menopause can also affect the level of dryness because it works in the same way by reducing your estrogen levels. Over-the-counter lubricants are really great start to use, however, some patients may need something different. If you feel like after a couple of tries this is not working for you, I would suggest you have a conversation with your healthcare providers, because there are some other prescription medications that can help with dryness and have really good efficacy on that. Over-the-counter lubricants, however, is a great start in addressing this.

[Sherry] thank you.

[Lynn] Hi, so it appears from your chapter and your talk that everyone with lung cancer has some issues with sexual health. So, if that were true then sexual dysfunction would be a major adverse effect for lung cancer and yet nobody seems to talk about this. If it's a normal response to having lung cancer, then it seems that we need to change the conversation around side effects, so how would you go about doing that?

[Loise] So lung cancer is a bit of a unique picture not everybody experiences sexual dysfunction during lung cancer treatment and that certainly goes for all

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cancers, as well. There's limited data to show how much, or what the percentage of people were getting treatment, have sexual dysfunction, this is not to say that there's not a large percent of people or patients during treatments who are getting lung cancer treatment. The conversation begins in the clinic with you and your provider, suddenly if you've noticed you have different changes and experiences during your intimate sessions with your partner, that would be my start and recommendation to bringing in into the conversation. Lung cancer treatments can cause sexual dysfunction either directly or indirectly and since the treatments are so vast the side effects as well may not be predictable from patient to patient. I would say having the conversation in the clinic, especially when you've noticed changes or you have concerns, early in the beginning before treatment starts would be the best place to have this conversation with your provider.

[Chris] Hello Louise I have a question for you, first of all your book in the document is wonderful, thank you so much. My question is around; do the different types of lung cancer treatments impact sexual intimacy more than others, in other words, like is a chemo more impactful or is there's the same kind of side effects for different types of treatments whether it's radiation or other more personalized medicine; and if so, what is more impactful to women versus men.

[Loise] Yes so lung cancer comes in different entities and with that different modalities of treatment that include surgery, radiation, and chemotherapy, and also targeted therapy each of which have different side effects and toxicity profiles. Additionally, to that just to complicate to the whole situation patients also react differently to that it would be hard to say which aspects of the treatment affect more than others, however there's data to suggest that some of the chemotherapy medications can affect fertility and that has been proven especially for the ALK agents like carboplatin. The rest of the treatment especially, you know radiation, we're not radiating close to the reproductive tract however some of the effects towards sexual dysfunction come from indirect effects like fatigue, anxiety from treatments, and this to some degree can affect more patients than others. There's not a standard, or there's no data suggesting, this affects women or men more just because there's a lot of factors, a lot of different entities towards lung cancer. Lung cancer is a complex diagnosis in itself and especially in the era of mutations. There's different treatments that come with it

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that are very individualized and patients have different ways and different side effect profiles, as well. Our health care providers are equipped with a knowledge for things to look out for and also as patients, it's good to have that conversation when you notice something feels different. I would bring it up with a healthcare provider. Being an advocate for yourself, having your partner advocate for you is a good important step. The provider is here to support you in whatever way possible, especially during this treatment.

[Chris] Real quick follow-up, I just wanted to ask on some of these treatments is it are they some of these side effects short term, do they typically go away over time or is this something are you seeing, where once you start having some of these side effects they're pretty much permanent?

[Loise] So some of the indirect side effects are more transient. We know that chemotherapy or targeted medication, radiation therapy, and surgery can cause fatigue and most of our patients after treatment, after a couple of weeks or even months. After treatment start feeling more energetic so we are reassured that some of these effects are temporary. That is not to say that there's some underlying permanent factors and this is very dependent on you know, medications that you're on again, knowing each medication that you're receiving may have different profile that may be temporary, or permanent, is one way of looking at it and certainly the healthcare provider can help tease out which features a little bit more long-term than others.

[Chris] Thank you.

[Loise] Your welcome.

[Marla] I think I'm ready to date again but what holds me back is two things; how do you get in the mood when especially where I've been off treatment for so long for two years it's like I'm still tired, and the other part of that is like what do you say to guys or you know whatever, what do you say to people; how do you present I'm not going to be able to breathe during this, you know, was too much for one guy I was trying to date. I don't know how to approach it with somebody that you're thinking about being intimate with. That's the big thing and then the side effects I've had from cancer itself the shortness of breath and the and I lose

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my voice after an hour or so of talking. And I mean how do you combat that any tips?

[Loise] Thanks Marla. And I just want to acknowledge that all these problems are very common and I understand you know someone being embarrassed about it, I just want to reassure you that it happens more commonly than you think and the healthcare providers are aware and they are a lot of supportive services that are integrated into cancer treatments. So this is totally normal, it's a situation that I'm glad that you've brought about it and thanks for sharing that with us. I know cancer treatments and you know the cancer diagnosis is a very complicated situation especially with the family dynamics, and the partner acknowledging the burden that cancer has on intimacy for both you and your partner is a really great first step. Sharing with your partner up front the concerns and some of the things that relate to cancer treatments may offer a good first step. Sometimes bringing the partner into your provided treatment visits just to see the other side, I know for most of our families and friends and people who've never experienced having cancer, or having a relative, or a partner with cancer, this is also a whole totally different experience for them bringing them into the provider visits and just seeing the other aspect and seeing what you're experiencing may offer some insight. There's a lot of cancer support groups for patients and partners out there some of the places Cancer Centers do have the support groups and services that they would be really happy to provide information for and to plug you in into those support groups, and finally counseling there cancer specialists that deal with counseling for patients and also families and partners. They have really good specialized tools to bring this conversation for both you and the partner together, so that we can do the next steps, you know first acknowledge and then what do we do from there and where do we go from there. You mentioned shortness of breath, there's some in this sexual health clinics they offer intimacy positions that may be very beneficial for patients who have experienced shortness of breath during their intimacy sessions. So it's really having this breath of knowledge and information that they are their management options for you and that I hope can give you their reassurance towards the next steps.

[Marla] Yeah this doubly hard because I want to start dating my old boyfriend just couldn't handle it, and now, it been a few years to even think about doing it again and going out and say oh it's great we have everything in common, oh yeah, by the way I have cancer stage four, you know it's want to play, you know it's kind of

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it's a little hard but you know maybe with these groups and stuff I can get some tips and maybe there'll be people there that met after they had cancer like me.

[Loise]So it's absolutely a tough place to be people who haven't had anyone they know with cancer may not know how hard it is on patient as well, so I would say you know having the support from cancer survivors and their partners would bring really helpful tips.

[Marla]Thank you, thanks appreciate it. Give it a shot.

[Sherry]Hey I have a question, I struggle with fatigue and I'm exhausted by early evening and I would like to be intimate with my partner but the fatigue sometimes is so bad, what are some things that I can do maybe to help overcome the fatigue?

[Loise] So fatigue, to be honest, is one of the most common symptom that our patients experience, not only during active treatment, even after treatment. It can go up to months and years after treatment; this is because in addition to having the burden of cancer diagnosis and survival treatments have been known they take a physical toll on your body. Having enough rest, I know it's easier said than done. It is a good step for some patients that I've talked with having a schedule has worked for them, scheduling in time for visits because this visits do stack up you know having all this patient provider visits having a good schedule for that and also having time to schedule for your own self-care. Sometimes we tend, we only think about the cancer and the treatment and we tend to forget that we also need to take care of ourselves, our feelings, our emotions, our bodies. We need to schedule that into a regular activity and not let cancer and cancer treatment and patient visits just run the show. Scheduling time with, also, your favorite activities, with your family, with your partner, with your favorite fur animals. Putting that into your schedule makes it more intentional for it and creates a little bit of time into this space that cancer can potentially overrun. So having little pockets of your own time is really important. Another way to combat fatigue, maintaining an active regimen, gentle exercises, doing daily walks, the body can decondition itself especially when your feeling fatigue the last thing you want to do is to get outside and walk; but however what walking does it brings in the feel-good hormones that come back to the fatigue. Nothing like running a marathon, just taking your favorite walk it could be a 10-minute daily activity, 20-

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minute daily activity and then taking a nap shortly afterward. All this does bring about your endorphin levels that can lower fatigue in your cells. A healthy diet is very important, maintaining a healthy diet and also hydration are other ways to combat the fatigue, and sleep as well it's important. Now to understand how much sleep deprivation can increase your fatigue levels, and I know during this treatment sleep can be a bit of an issue having sleep hygiene, and also there's other ways to incorporate sleep into your regimen that can be with the help of your health care provider. So, it's good to let them know that you're struggling with sleep, and they can come up with ways to help you manage that.

[Sherry] Yeah I think that's my biggest problem, is sleep, and so that I find myself exhausted by evening time because I haven't slept well.

[Loise] Yes at night, absolutely lack of sleep is one of the things that can really increase your fatigue levels so this is a conversation, especially if you've struggled with it for a while, to bring up with your provider. We have good ways to manage sleep both non-medication and both medication, to help you with that. So it's a good thing to discuss with your provider as well. I also want to bring up another aspect of fatigue that may be overlooked. There's some underlying factors that can contribute to fatigue a result of side effects that could be low blood counts, so it's important in as much you know, as you're trying to do this you notice your fatigue is just worsening, to let your provider know and they can run a couple of tests to determine exactly; there could be an underlying factor beneath it like low blood counts and anemia. So, this is one of the things that can be teased out during your health care provider visits.

[Sherry] Thanks for all the tips.

[Loise] You're welcome.

[Lynn] Just as an addendum, menopause can also make you tired.

[Loise] absolutely, absolutely.

[Lynn] and that goes away over time

[Marla] I have the apnea so that's going to help a lot when I get my machine next week. I also just finished four iron transfusions over the last couple weeks, those

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make you tired, but then they're supposed to pep you up in a couple of weeks; so that might be it too and he said that was probably from the treatments; and I've had it for a couple years and didn't even know it because it's not something they test for and they tested my vitamin D, it was very low; that contributes to it and calcium. So now I'm on a bunch of more pills because why not. but it's it is making a difference. I can feel it so it's might be time for a full checkup because they weren't doing that for me because they were saying oh well you're stage four let's just concentrate right on the cancer; never mind everything else. Well now my doctor says well now we have to treat the rest of you because you're going to be around for a while and bug me. So let's get it all done. So they ran every test in the world so it's something you might want to think of if you haven't had it done in a while.

[Loise] Absolutely and thank you for those comments. We want to fight the cancer, but we also want to make sure our patients have really good quality of life; there's a life after cancer.

[Chris]I was going to say we've had uh a couple in our meetings, integrative oncologists actually come in and we met with them and they actually went through everything that my wife ate, how she ate, the different treatments she had been on and they looked for like did not only did all the tests and all that but he actually looked like her holistic body and see where things could actually help out. So that might be another. I'm still learning all these different ones, but that might be somebody you might want to look up as an integrative oncologist because they're really specialized in your whole-body health.

[Sherry] Yeah good idea,

[Loise] That's actually a topic that when I was looking at Chris's your question about integrative medicine, I was going to talk about this new integrating aspects of non-traditional medicine. It's been around for years but now. It's now making it into mainstream cancer treatment and it's called integrative oncology, so thank you Chris for bringing that up. As Chris mentioned they offer holistic therapy. They offer chiropractic medicine, they can also offer massage therapy services, dietary services. It's a whole new world and I do appreciate that they're now acknowledging that you know we need to treat the patient holistically and look

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the patient in totality and this can certainly address most of the concerns that come with dealing with cancer and cancer treatments.

[Lynn] so I'm going to totally change the subject and it doesn't affect any of us sitting here but I have a number of acquaintances who are very young and have been diagnosed under age 40 with lung cancer. I mean something we never thought about but they weren't directly told that treatment might affect their fertility and we know it can. So how do we educate, you know doctors and nurses, to make sure that everybody knows up front what might happen later.

[Loise] Yeah thanks Lynn for that question. So, as we know most therapies especially, chemotherapy can affect your fertility. For radiation and surgery, it's a bit of a unique situation since we're not directly affecting reproductive function but chemotherapy certainly especially ALK agents have been known to affect directly fertility. Some of the questions during intake may ask your desire for fertility and also so are you looking to increase your family or have kids in the future; and this is a conversation that should be integrated into your cancer treatment and therapy. I'm sorry I'm not in a good position to answer how your friends may have not gotten around to the conversation but certainly this is something that our health care providers know; especially our chemotherapy doctors who are the oncologists and it should be standard in my opinion. Especially if looking to preserve fertility is considered. There are really good fertility preservation options available depending on number of factors and again this is tailored to each individual patient. I don't know if I answered your question?

[Lynn] Right, I mean and you know it's quite possible that the diagnosis from cancer is overwhelming.

[Loise] Exactly

[Lynn] And it is quite possible that people don't hear everything because they're just like, "why me". So, it may be something that just needs to be revisited with some people after the diagnosis.

[Loise] I agree most of my patients when I see them the third, fourth time, and I always have you know the conversations and they tell me, "Oh this sounds new to

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me”; and I understand you know this ,probably is the fourth time I'm telling them but you know just having that burden of cancer and the beginning everything is all sort of information is coming up to you. It's really hard just to sort out everything you're hearing at that time; but I agree it's a conversation that should be revisited not only early enough during the treatment but also in the later stages of treatment.

[Chris] And Lynn, I was going to say I don't know if you want to call it caregiver, I was it was my wife, so I was a helper, and I went to all the meetings with the oncologists, the surgeons and so forth, so I think sometimes it's really helpful to have a second person with you, if not a third, because sometimes when you're going through it I've seen her when she's going through the chemo and she could hardly get off the bed. So, I mean it was pretty much me answering a lot of the questions at sometimes because she's just not feeling well enough to do it. So, I think maybe everybody should have at least one other person go with them when they go to these doctor's appointments so they can help take notes and mental notes if nothing else.

[Loise) I agree the providers should be able as well to go over all the information, all the answers, all the questions, all the concerns, as much as patient wants. The information it really isn't a burden for the providers, we want to be as supportive as possible, so going over this information is certainly something the providers should be doing as well.

[Marla] Chris, yy doctor's office gave us, on your first visit, a folder and with all sorts of information; but one of them was common questions and answers you know like a fact thing and so it answered a lot of that, but it also in the back of it had several sheets of paper in there for you to take notes on and a pen. They included everything and that was something maybe you could bring up to your doctor's office, is to make up a packet like that that has everything in it that they can refer back to because I brought my sister with who's 10 years younger than me and very with it and a big manager at a bank or something; even she missed some information, and I definitely did and I'm a nurse. And at the time even though I was sick I still had been working so I felt like I was with it anyway, and we both missed stuff; but it was written in that thing, thankfully in that pamphlet, so suggest it and tell your doctor you'll help make it up and then it'll have to go through committees but it'll get there, for the new people.

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[Lynn] And sometimes, again having an overwhelming diagnosis, you don't know the questions to ask. It takes a while to digest that and figure that out.

[Chris] Well and I think looking back and we didn't have this, but that's why my wife started her own nonprofit to help. I think having a community of folks that are going through it with you is extremely important because if you don't get those questions sometimes, like you're on Facebook or however you decide to connect with others, you can at least have that camaraderie that says, Hey, I'm going through this too, how are you doing, you have that common bond and that I think is really supportive because you can ask questions there and then they may have good questions you never thought of asking so the next time you go to your doctor you can get that information, so I think there's a there's a real good idea to having bond and commonality between. Make friends that are also in the cancer world with you.

[Chris] I kind of wanted to ask a little bit more and like some of the issues with like sexual intimacy problems. Can they be prevented or treated or managed in advance of the different treatments? In other words, are there are certain foods, certain things you can do to even reduce or prevent the impacts? And we had a session on Eastern medicine, I'm wondering if some of that would play in some of this.

[Loise] Yeah, thanks for the question. So, there's limited data to show what intervention before treatment may help with some of the things or factors that are related to sexual dysfunction. However, having a good exercise regimen, and by exercise, I mean gentle exercises, walks, having a healthy diet and hydration. Being in good condition certainly does help you mitigate the level of side effects that you may be getting, even before the treatment. This is also very individualized, it differs from patient to patient and there's no great answer or any data to show that some of this can be prevented well beforehand. Data suggests patients who are in good performance status tend to do much better in terms of side effects as compared to patients who are not in very good physical state. However, that being said, you know, just continue maintaining good diet, exercise, hydration and this does make the treatments and the side effects to be better tolerated.

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[Chris] Thank you.

[Loise] You're welcome.

[Sherry] So I read in your chapter about using lidocaine, I have vaginal atrophy, would lidocaine help with painful sex and what areas do you apply it to is it inside the vagina is it outside?

[Loise] Yeah thank you for that question. I want to address your question just from the start, so vaginal atrophy can be caused by different things, it can be due to menopause, it can be also due to side effects from treatment, especially chemotherapy which may reduce your estrogen levels causing atrophy and dryness. The best thing before trying over the counter lidocaine or other topical applications is to have an evaluation with your health care provider. They can tease out the exact causes and identify if there any underlying factors that are causing vaginal atrophy. Having evaluation by your health care provider can identify some of the underlying causes and also help you know the management options that are available, and as we mentioned use moisturizers and lidocaine can be one of the areas that can be used; hesitant to saying which areas that you should use the lidocaine in because I want the health care provider to have the best recommendation for you after having the evaluation visit, but one way I would start would be just using over the counter lubricants and then having this conversation and evaluation with the health care provider.

[Sherry] Okay

[Chris] I wanted to ask you a real quick question I know there's a whole bunch of different you know specialists in certain areas but it's a little confusing to some of us where who do we reach out to for what issue especially with sexual intimacy and so forth, so if I have questions for my regular oncologist I know sometimes I need to go to a different doctor for different things, so who would I go to I've heard several issues here what specialist would you recommend going to because it does get confusing to us sometimes who to see. Thank you.

[Loise] It does get confusing. I know there's a whole team that's taking care of you and it suddenly can get lost as to who to ask what kind of questions. In your cancer team there's the primary oncologist and that can be the radiation

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oncologist a medical oncologist ,or your surgical oncologist, but in your team there's always one oncologist who's sort of managing your cancer team and that's the person I would go to for these kinds of questions; and the reason I would go to them is because they can make any, you know, referrals to any, sexual health care clinics that can provide specialized care. However, that's not to say you cannot ask anyone in the team, anyone in the team would be happy to make the referral and the recommendation. I would not hesitate to ask anyone in your team as they are well equipped and they can offer referrals uh for sexual health clinics. I want to bring to light to the group that there are sexual health clinics that deal with sexual dysfunction and intimacy issues and these are referrals that actually covered by insurance and that's why you know asking your provider to make this referral and recommendation is something that they can do so that you can get appropriate care that is covered by your insurance, as well.

[Chris] Thank you very much. I know quality of life is so important too so I mean just because you get a cancer diagnosis doesn't mean everything has to stop so I really appreciate that, thank you,

[Loise] Absolutely, yeah cancer should not and will not be running your show and we always want to take care of your whole body in totality. In addition to addressing cancer there's so many layers to it and holistically we should be able to think of the patient as a whole. Thank you, thanks.

[Sherry I actually had a question about counseling. Where do you find counseling that helps the cancer patient and their partner understand the challenges with the lack of intimacy and the feelings that you have of guilt during cancer treatment?

[Loise] Yeah, thanks for the question. Counseling services are and should be integrated into the cancer groups or cancer centers that's taking care of you. Sometimes patients may not know that they have these resources so it's good to let your health care provider know this is what you need and they will be more than happy to give you the resources that are Available and present for you. Also, your providers should be able to make referrals for you to sexual health clinics that are specialized in dealing with sexual dysfunction especially with cancer care. These are specialists who've been trained and practice in dealing with sexual dysfunction and they see an array of patients and with that cancer patients with

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different side effects cancer support groups are also very, very helpful; and I know different cancer centers may list the cancer support groups that they have and certainly coming together with in these groups and having discussions may also broaden your knowledge and the resources, as to clinics that you may have for addressing sexual dysfunction and intimacy issues.

[Sherry] I know I'm part of some support groups but it seems like a topic that's not brought up much and I don't know if people expect that they're supposed to live and that's their life now instead of addressing it; so I think I feel more comfortable now, you know approaching it maybe in some of the support group, so we can open the get the conversation going and you know people can seek the help that's out there that most of us don't even know about.

[Loise] Absolutely and I also want to acknowledge that these are conversations in as much as so many patients are experiencing it. This is something that we need to talk about to advocate, both as you know even as providers, we need to acknowledge and to have a lot of interventions and ways to acknowledge that quality of life amongst our patients and in that sexual health and intimacy is one of the key areas that I feel that has been overlooked. And we should certainly bring it to light.

[Sherry] Yeah, I think it could save a lot of relationships.

[Chris] I'd like to go a little bit different direction. I guess some of the things and I was, I know I was never told this, but I've been wondering about this; is what precautions should be used when patients are in treatment. I'm actually a caregiver so when they're in treatment should condoms be used during all types of treatments? Is there certain treatments that are more potential dangerous to the your partner, and when and should, and how long after a treatment should they be used?

[Loise] So lung cancer is a complex diagnosis and has different entities and with that different treatments. Different treatments include medications like chemotherapy, they can also include surgery and radiation therapy. Barrier precautions however, may not be needed for radiation or for surgical aspect of the treatment. Different medications, however, are a whole different picture the thought behind it is that some of the medications can be excreted into the bodily

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fluids, certainly barrier precautions for some of this are typically recommended. This is hard to say or hard to list the medications in which you need special precautions, but certainly if you're receiving chemotherapy your medical oncologist should be able to advise you as to how long you need to use the special precautions and barrier prevention measures. Other aspects of treatment, especially if you're trying to have a child should also be brought forward when you're trying to conceive. Conversations like this, you should be able to bring this forward to your provider. We know that these treatments can not only affect your fertility but can also affect the chromosomal makeup over your spermatozoa or your or your eggs. I would say if you're trying to conceive and if you're on active chemotherapy management certainly barrier precautions is a conversation the medical oncologist should be able to provide.

[music]