





















## Sexuality and Lung Cancer Patient Panel

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.

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