

Sexuality and Intimacy in Cancer Survivorship



PATIENTS/CAREGIVERS TRANSCRIPT

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Hi, my name is Sage Bolte, MSW, LCSW, OSW-C. I'm an oncology counselor at Life with Cancer®, an Inova Health System service in northern Virginia. I've been in oncology social work for about 7 years, and have developed a strong interest in the area of sexuality and intimacy, specifically in how cancer and its treatments impact sexual function and intimacy in relationships.

Often when I am talking about sexuality and intimacy with patient groups, they will say, "Gosh, Sage, that's the last thing on my mind. I'm so tired all the time," and I absolutely understand and respect that. But when I'm talking about sexuality, I'm not just talking about the act of sex. I'm also talking about your intimate relationships, or intimacy, as well as sexual function, or how you feel about yourself as a man or a woman.

And although, during your treatments, sex or your sexual function may not be as important to you, it may become an issue important to you after your treatments or in your follow-up appointments with your physicians.

During treatment, as you well know, many times we feel isolated – more alone. We feel like people don't "get it," and we may find ourselves disconnecting or isolating ourselves from our friends, our partner, our family, or our children. So it's important to recognize that cancer impacts many aspects of our lives.

It impacts our relationships in a very profound way. If we aren't talking about it or addressing it, we can find ourselves 5 years down the road feeling very isolated and feeling very alone. If we're experiencing a sexual dysfunction, we may feel ashamed by it and not want to bring it up with our partner, or not want to bring it up with our healthcare professional.

It's important to acknowledge that many of the sexual dysfunctions that we're going to talk about throughout this segment are very common, and it is absolutely critical that you bring it up with your healthcare professional, so that you can improve not only your sexual function but also your quality of life.

A lot of the treatments that you've been given to treat your cancer are doing a great job at treating your cancer. But as you know, there are many side effects of treatment, such as fatigue, pain, nausea, and we give medications to help manage those side effects.

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However, both the medications you're given to manage your side effects, as well as the medications you're given to make your cancer better or to treat your cancer can impact your sexual function and the way you view yourself as a man or a woman.

When we're talking about chemotherapy, the most common side effect for women is vaginal dryness, and that's due to a couple of reasons: 1) we know that chemotherapy is a drying agent; and 2) a lot of women experience menopausal symptoms that exacerbate the vaginal dryness. If you aren't comfortable asking your physician about vaginal dryness, you may want to look for some resources on how to address that issue by yourself.

Beyond vaginal dryness, we also know that radiation and stem cell transplantation also impact sexual function for both men and women. Men may experience less of an erection or their erection may not be as firm. Men and women may experience high levels of fatigue, which again impacts sexual function, because you may not be as interested in sex or you may not have the energy to have sex.

It also may impact your intimate relationships, because again as I said earlier, when you're not feeling great that definitely impacts how we choose to interact with our partners or our friends, and we may find ourselves again isolating more.

What we know about chemotherapy, radiation, stem cell transplants, and a lot of the anti-emetic drugs that you will receive to help counteract the side effects, is that these treatments impact, in general, much of the sexual function. As I mentioned before, erection difficulties, vaginal dryness, libido, and your orgasm intensity, can be addressed by your healthcare professional. We will give you some specifics on how to address it just briefly in this clip.

If you are a pediatric or adolescent survivor, you may have some concerns down the road regarding sexual function or how treatments might impact your sexual function beyond just fertility. One of the things we do know is that girls who were given stem cell transplants at age 18 or younger are usually not at great risk for premature ovarian failure or early menopause, but you may be experiencing some of those side effects or symptoms. If you have not had a period for a long period of time, if you experience a lot of breast tenderness, or if you experience changes in your menstrual cycle, you may want to draw that to the attention of your healthcare team so they can make sure to address that, and they can give you medication to counteract your going into a menopausal state.

Some of the other concerns that pediatric and adolescent survivors experience as it relates to sexual function, surrounds the longevity of your treatment. There is a lot of social isolation during your treatment, and you may have concerns about how you talk about it or disclose the fact that you are a cancer survivor. Many adolescent and pediatric survivors experience long treatment times, which result in lots of isolation and social isolation. You may be wondering, "How do I disclose this? I'm interested in dating someone. How do I talk about being a

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survivor?" You may wonder how you might go about discussing some of the changes in your body that have occurred because of treatment.

You may know that your body looks different because of the cancer treatments. How do you talk about the scars, or how do you talk about the skin changes? It's important to find someone you can talk to about this, whether it's talking to a friend, a counselor, a family member, your physician, or your healthcare team. Finding ways to talk about this, and mapping out in your own way how you might go about disclosing your cancer history to someone you're interested in dating, is important.

Another common concern or question that pediatric and adolescent survivors bring up is the issue of sexual maturation or underdevelopment. Some boys may notice that their penis size is smaller or their testicles never fully developed because of treatments.

Girls may notice that they're underdeveloped in size, or their breasts are underdeveloped. It's important if you have concerns about this, to bring it up with your healthcare providers. This is a normal conversation that they are comfortable talking about, but they probably won't initiate the discussion with you. You will need to initiate this with them. They can then talk to you about techniques, methods, or ways that you might go about addressing these concerns.

Being a young adult survivor, between the ages of 18 and 38, you may be experiencing some concerns about dating and disclosure, concerns about how your sexual function may have changed, and concerns regarding fertility issues or intimacy issues after your cancer diagnosis.

Many people diagnosed as a young adult experience significant changes and social isolation due to the treatment requirements, especially during this time of life. So you may have been in college and had to move home in order to get your treatment.

That can really impact how you feel about yourself, how your relationships continued after college or maybe during college. Maybe if you were in a relationship with someone sexually, that relationship may have ended or there may be some complications.

Common questions that young adults have are related to fertility issues and sexual function issues. Most common for women is the issue of vaginal dryness. They weren't informed or didn't know that they may experience heightened vaginal dryness or discomfort with sex. If this is an issue for you, I would absolutely recommend that you bring this to the attention of your healthcare team. There are lubricants that can make it more pleasurable and help ease the discomfort of vaginal dryness. For men, you may be concerned that your erection may not be as firm, and again you may want to bring this to the attention of your healthcare team.

As always with any of these concerns, you can seek out your own therapist that specializes in sexuality issues, a sex therapist, an oncology counselor, or an oncology social worker, who may be able to better address these issues.

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One of the other most common concerns of young adults is body image concerns, and the changes in body image from the treatments, whether it's scars, skin changes, or skin discoloration. Finding ways to cope with those changes is going to be an important part of your healing process and an important part of enhancing your sexual self.

If you can just spend time every day affirming yourself, giving yourself positive thoughts, or saying to yourself, "I will do everything I can to love and enhance my body and its healing. I will do everything I can to love and enhance the way I feel about myself." As cheesy as it may sound, really and truly, if we can wake up every day and say something positive about ourselves, we actually might start to believe it.

If you are single, or were single when you were diagnosed, unfortunately, you might not have been told about the sexual dysfunction issues that result from your treatments. You may experience new concerns around vaginal dryness or erection difficulties, and these are important to address with your healthcare provider or your healthcare team.

If you are single and you're currently thinking, "I think I want to date, but how do I talk about my disease, or how do I talk about being a cancer survivor?" There are some ways you can practice. One of the ways is to engage in a conversation with your best friend; practice talking about your disease and your history of cancer.

Cancer is just a small part of who you are in your history. It does not define you. Just as you would talk about how many dogs and cats you have, where your parents live, or where you grew up, cancer is just a part of your history. It doesn't define you. So practice talking about your survivorship and find a script that works for you to disclose to someone you're interested in or dating that you had cancer, or have cancer.

Another technique that you might want to use, if you're interested in dating someone and want to learn when to disclose or how to disclose, is to decide what date number you're going to disclose on. One of my good friends is a survivor and she has the rule that by date #4 she discloses to the person that she's a survivor. Her theory is that by date #4 she's not fully invested yet but she knows she likes the person and wants to have date #5. So to avoid her own pain, she goes ahead and tells her date, and if that person chooses to go on date #5, #6, or #7, her date goes in knowing that there's a history of cancer. And if the person chooses not to, then she doesn't feel hurt by the decision.

Being a single survivor also means that somebody may not be talking to you about just your own sexual health. So it's absolutely normal to ask questions about safe sex, masturbation, sexual function, or maybe some of your own sexual function concerns with your healthcare team.

If you have some real concerns, it might be wise for you to seek out an oncology social worker or a sex therapist to talk a little bit more in detail about your concern as it relates to sexual

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function. Getting to know your body again after treatment is going to be one of the best gifts you give to yourself. Figure out what feels good now, because what felt good before cancer may no longer feel good to you now.

That whole idea of the “new normal” applies to the sexual self just as much as it does to every other area of your life. So get to know your body again. Figure out what sensations feel good, what sensations don’t feel good, where you’re turned on now, where maybe you weren’t turned on before; when you do engage in a sexual relationship, you are able to guide your partner through without feeling any pain, discomfort, or embarrassment.

If you have advanced disease, or metastatic disease, you may have some real questions around safety issues, sexual function, and enhancing your intimacy. Sex is absolutely safe as long as you’re aware of your blood counts, you know what your immune system is doing, and you ask your healthcare professional if it is safe.

You may find that your sexual function is not as high as it used to be, or you may find that your desire or your libido is really low right now. You may want to look at other techniques to enhance your sexual intimacy with your partner or with yourself. It may mean that you spend time in bed together stroking each other, or spend time just connecting. It may mean that you watch a romantic movie together. It may mean that you have your children crawl in bed with you and read a story to you. It may mean that you find ways to connect with your friends in an environment that is conducive to your own needs. If you find that you’re more tired in the afternoon, maybe you need to schedule time with your partner or your friends for those moments of intimacy at the times when you feel most refreshed, possibly in the morning or late in the afternoon after you’ve taken a nap.

If you have pain, it’s absolutely essential that you manage your pain first. With managing your pain, I know there are other side effects such as fatigue (or tiredness) or lowered sexual function with some of the pain medications. However, if you want to enhance your intimacy, or if you do want to engage in any kind of sexual encounter with your partner or with yourself, it is important to manage your pain first.

Other concerns that advanced disease or metastatic patients may have concern sexual function itself. If you have questions about sexual function, you can ask your healthcare team for suggestions on how to enhance your sexual function. They may be able to prescribe something to enhance your sexual function.

They may want to talk to you about vaginal lubrication, or they may be able to talk to you about other devices that may aid in enhancing your sexual function. If you find that you have a lot of joint pain, you may want to put some pillows underneath your joints to help cushion that discomfort and cushion the weight.

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There are many ways to be sexually intimate without the act of sex. Laying naked together or having your partner bathe you can be some of the most intimate and sexually intimate moments you can share. If you are single and have advanced disease, make sure that you are initiating or communicating your needs about intimacy.

Make sure that you are asking your friends or family members to come over at times when you are most alert, when you feel your best, so that you can benefit from engaging in those relationships.

Sexuality, sexual function, and your intimate relationships are a huge part of your quality of life, so it is absolutely critical that you bring up this issue with someone you trust. My recommendation is to discuss with someone you trust on your oncology healthcare team – whether it's your physician, your nurse, your oncology social worker, or a counselor that's available to you – your concerns, have them address what your needs may be, and give you some tips on how you might enhance your sexuality and sexual function.

Another option is to find a certified sex therapist to help address some of your concerns, which you can go to alone or together with your partner. If you're in a partnership, you and your partner can seek out a sex therapist to help enhance your sexual function, or to help you adjust and adapt to the diagnosis of cancer sexually.

You might be able to find a sex therapist online at the American Association of Sexuality Educators, Counselors, and Therapists (www.aasect.org) website. A certified sex therapist could assist you with managing some of your sexual health concerns. Again, an oncology social worker is always available to at least find resources for you and maybe find techniques and ways that you can talk about your sexual health concerns with either your partner, your friends, or your healthcare team.

Sexuality and intimacy are just one part of your life and your quality of life, but a very real part of your quality of life. From the cancer and its diagnosis there have been, I'm sure, a lot of "new normals" that you've had to readdress, rescript, or relearn. One of them may be your sexual function or your intimate relationships.

This is a really normal process that most survivors go through in trying to redefine what their "new normal" is as it relates to their sexual self. Maybe what worked for you before doesn't work for you now, and you need to find new techniques to maintain sexual intimacy with your partner or yourself. Because again, what worked before or prior to cancer, no longer works.

It may be good to find a healthcare professional, such as an oncology social worker or one of the members on your oncology team, to help you address some of your concerns around sexuality and how to redefine that "new normal," maybe coming up with some new ideas on how you might maintain or enhance your intimate relationship if sex isn't a possibility.

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You also want to make sure that you feel comfortable talking to your healthcare team. If there is someone on your healthcare team that you feel particularly close to or you feel you can connect with, open up with them when you have concerns. They're trained to help address the issues of sexuality and sexual function and want to help you. Again, the fact sheet that *The Leukemia & Lymphoma Society* has on sexuality can be a great starting place for you.

We've covered just a little bit in this time together, and I know you may have a lot of other questions, so please contact your healthcare provider if you have any further questions. My contact information is available on this website. Please feel free to send me an e-mail.

And if you have any other questions or concerns, find someone who you can trust, who can help you address some of your issues as they relate to sexuality and intimacy. This is a very real part of your quality of life and a very real part of your survivorship.

Thank you to *The Leukemia & Lymphoma Society* for taking time out to address the issues and concerns surrounding sexuality and cancer.