

## **Sexuality and Intimacy After Cancer**

**Sage Bolte, MSW, LCSW, OSW-C**  
**March 11, 2008 • 12:00pm ET**

OPERATOR: Hello, everyone, and welcome to *Sexuality and Intimacy After Cancer*, a free telephone education program. It is my pleasure to introduce your moderator, Carson Pattillo.

CARSON PATTILLO: Thank you and hello, everyone. My name is Carson Pattillo. I am the Vice President of National Education Programs for The Leukemia & Lymphoma Society. And on behalf of LLS we thank you all for choosing to spend your time with us today. We welcome all of you.

Today's program, *Sexuality and Intimacy After Cancer*, features Sage Bolte and we thank Ms. Bolte for sharing her time and expertise with us today.

I would also like to note that today's program is solely funded by LLS.

You all should have received a packet of information for today's program, including an order form for LLS materials and an evaluation form for you to fill out for today's program. And for your convenience, all participants may also visit our Online Participant Evaluation Center, and you can do that by visiting [www.LLS.org/eval](http://www.LLS.org/eval) to complete your evaluation online. A code will be given at the end of today's program for nurses and social workers to enter for the online continuing education evaluation.

After our keynote presentation by Ms. Bolte, we will open up the program to questions from all of you, our telephone audience. We have over 1,400 individuals registered for today's program via telephone from all over the country, in addition to several international participants from Brazil, India, Taiwan, Iraq, Kenya, Uruguay and Pakistan. A special welcome to all of you.

If we're not able to get to your questions today, you can call the LLS Information Resource Center. It's a toll-free number. The number is 1-800-955-4572. That number is also on the materials that were included in your packet. Dialing that number will connect you with one of our information specialists who can answer your questions or help you obtain more information.

And as a note, we're also audiotaping and transcribing today's live program for future posting on the LLS Web site. The program archive will be available for you to access in several weeks.

Before I introduce Sage Bolte, I just wanted to say we're so fortunate to have her with us today. Sage is a renowned authority on sexuality and intimacy in cancer survivorship and we at LLS thank her and Life with Cancer® and INOVA Healthcare Services for taking the time to present this important topic today.

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CARSON PATTILLO: For those of you who are new to us, The Leukemia & Lymphoma Society is committed to bringing you the most up-to-date information about your blood cancer. We know it's important for you to stay current, so that you can work with your physician to determine the best options for your outcomes. Our vision at LLS is that one day the great majority of people who have been diagnosed with a blood cancer will be cured or they will manage their illness with good quality of life. This teleconference is one step on the road of your journey to manage your life with a blood cancer.

LLS is the world's largest voluntary health organization, dedicated to funding blood cancer research, education, patient services, and since its founding in 1949, LLS has invested more than \$551 million in research, specifically targeting blood cancers. We will continue to invest in research for cures and programs and services to improve the quality of life for patients and their families. So we are here for you.

It's now my pleasure to introduce our guest expert speaker, Sage Bolte. Sage currently is an oncology counselor in the Breast Cancer Program and Life with Cancer, part of INOVA Cancer Services in Fairfax, Virginia. Sage recently completed her course work for her doctorate in social work at Catholic University in Washington, DC, and her dissertation will be on assessing the impact that cancer and its treatments have on young adult cancer survivors' sexual self. She recently completed a study assessing the knowledge, comfort, attitude and approach of oncology social workers toward patient sexuality, and Sage hopes to continue to raise awareness on the importance of bringing a holistic approach to medical care to patients and families as they redefine their lives and sexual and intimate relationships in the context of a chronic illness.

We're so thrilled to have Sage with us. You can read her biography at length in the packet that was included. Sage, I'm now going to turn the program over to you.

BOLTE: Thanks, Carson. Hello to everyone around the world and in the United States. I welcome you and appreciate your time with us today for the next hour.

I'm going to take the next 40 minutes to hopefully answer some of the questions that were e-mailed in as well as then take the next 15 to 20 minutes during Q&A to answer questions that you may have as well, that I don't touch on during this talk.

So today we're going to talk about sexuality and intimacy after cancer. What I hope to do is talk about and define sexuality and intimacy, dispel myths about

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cancer and sexuality and intimacy, look at the specific impact of cancer treatments on sexuality and intimacy, and then talk about options to help manage difficulties with sexual function as well as intimate relationships.

When I'm talking about sexuality, I'm not just talking about the act of sex or intercourse, but really how you define yourself as a man or a woman and how your culture, your religion, your family values, all of that plays into how you define yourself sexually, as well as who you're attracted to, who you engage in sexual practices with and the kind of sexual practices you engage in.

Intimacy is really a human need and it can also be within a sexual context, but a lot of us have many intimate relationships with people that we're not sexually engaged in, and those intimate relationships, as well as our own sexuality, can absolutely be impacted by a cancer diagnosis and its treatments.

I know that sexuality and intimacy are not life or death issues, but they're very real quality of life issues. I appreciate The Leukemia & Lymphoma Society in recognizing that this is a major quality of life issue for people, both during treatment, as well as those of you who are now survivors after treatment and now are working through some of the ramifications of what the diagnosis and treatments really mean on redefining both your sexual self and your intimate relationships.

You know, sexuality really can signify parts of you that say "I'm alive, I'm human." It also can define acceptance and validation by your partner when your partner reaches out to touch you, or validate that you are still attracted or attractive to them. Resuming intimate relationships, whether they're sexual or not, is one way of feeling that life has resumed back to somewhat normal again. Or how we may say that "new normal." It may not look the way it looked before cancer, but it's starting to feel a little bit more regular or normal.

Some of the myths I want to address just right up front that I hear from patients when I'm working both with individuals as well as couples around sexuality and intimacy after cancer, are some of the following:

One being, if we can't have intercourse, it isn't worth getting aroused. I hear that a lot from people and again, whether they're talking about sexual pleasure with themselves or as a couple, that if they can't complete that course, that it isn't worth getting aroused. I really challenge that because you can have a very sexually intimate relationship with a partner or with yourself without the act of intercourse.

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One of the questions I hear a lot is “Can I pass my cancer on?” or “Are you sure that my cancer isn’t contagious?” As far as we know, all of the cancers right now, other than some viruses, cannot be passed on to your partner, that you can have safe sex and not worry about transmitting a cancer. As well as with treatments. Some people are also concerned of passing on, “Can I pass my chemotherapy on to my partner or the radiation?” And although there is some indication that if you have sexual intercourse within 48 hours of treatment of chemotherapy specifically, that your partner may develop a slight rash or irritation, but the partner does not absorb the chemotherapy in a way that’s toxic. So using a condom or protection within 48 hours of treatment would be a smart thing to do.

The other myth I hear is “This should be the last thing on my mind, I should just be glad to be alive.” I really struggle with that as a clinician as well as a woman in thinking, you know, part of regaining your life is really getting some of your life and what was important to you before cancer back. If obtaining some more of your sexual self or enhancing your sexual self as well as your intimate relationships is important, and it’s one of the things that comes out of maybe your cancer and learning more about yourself, then that’s a fabulous thing. It absolutely is a critical part of your quality of life.

“It doesn’t matter, I’m single.” I hear that a lot from the people I work with who are single and you know, going back to the definition of sexuality, sexuality is really all about who you are as a man or a woman and all the things that impact that in your sexual practices. So whether you are single or partnered, sexuality is a huge component of our life.

The other one I hear is “Sex is a failure if both partners don’t reach orgasm.” I know cancer and its treatments – we’ll talk about this more in-depth in a little bit – absolutely affect orgasmic ability, libidic response, and it can impact how a person or a couple interact sexually because things change after treatment. But you can still achieve a wonderfully intimate and sexual relationship even if you can’t reach orgasm.

Some of the other statements, and we’ll talk about this later, is “No one will want me if they know I’ve had cancer,” or “How will I even tell someone that I’ve had cancer?” This is a hard one for me to answer because there is no magic answer to this. But I can say that I’ve seen successful relationships develop after cancer and people who have been very willing to be in a relationship with someone post-diagnosis.

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And then this idea of “I’ll never feel sexy again,” or “I’ll never feel sexual again,” or “I’ll never feel good about myself again.” I think after treatment there is an awareness of how much your body has changed and there is this feeling sometimes of hopelessness, that it’s not going to feel the way it did again. But patience and some of the techniques we’ll talk about in a little while can help you regain a sense of sexual identity, a sense of sexual self and more confidence in that sexual self and feeling confident in what you have to bring.

So let’s talk a little more in detail about how exactly cancer impacts intimacy and sex drive. We’re going to look at the physical, the psychological and the social impact. The reason I include this is I think it’s really important for all of us to be aware that it’s not just a cancer diagnosis and the emotional impact that has on our body, and our emotions that impacts our sexual self or our sexual function and our intimate relationships, but also the treatments themselves.

We know that 40% to 100% of persons who’ve been diagnosed with cancer will at some point in their cancer journey, whether after treatment or during treatment, experience some form or change in their sexual function. These are not at all permanent or not all of them are permanent, but a significant number of people will experience a change in their sexual function. Some of this may be due to surgery, with physical changes that occur like scarring, having an ostomy placed or disfigurement that takes place. Impotence and anorgasmia can happen. The sensation changes when you’ve had surgery. Especially for a woman who’s had a mastectomy, when the breasts’ sensations have changed, that can have an enormous impact on sexual function and sexual desire. Surgery can also impact incontinence or the ability to control your bowel. The pain around the surgical area. Some people are at risk for lymphedema. All of those impact some individuals’ willingness to try to engage in sexual intercourse if they’re worried about pain or they’re worried about incontinence.

With radiation, we have the fatigue and that’s not just during treatment. There’s that accumulative effect of radiation, so the fatigue is felt later. That of course impacts your sexual desire and your sexual function. If you’re tired, you’re not going to have the energy to engage in a sexually intimate relationship. If you’ve had radiation to the pelvic area, there’s vaginal dryness as well as infertility concerns, skin discomfort and irritation. If you’ve also had radiation to anywhere in the pelvic or abdominal area, vaginal stenosis can be a concern, which is the narrowing of the vaginal canal. When that happens it can lead to painful sex and discomfort for the woman.

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Bowel and bladder problems can happen after radiation in the pelvic area, which, if you're concerned about incontinence or bowel and bladder problems, you may be less likely to engage in a sexual relationship. So discussing techniques on how to manage that and find ways to work around it is going to be really important to you.

Again, with radiation, the only risk to fertility is if you've had radiation in the pelvic region and you want to talk to your oncologist specifically about what your risks are. But if you've had other radiation to chest or neck or other parts of your body, that doesn't seem to have a significant impact on fertility.

What about chemotherapy? One of the biggest complaints I hear from people is this idea of "chemobrain." We've read a lot about it and people always look at me strange when I talk about chemobrain and sexuality. But actually I see it very closely linked in how it affects a person's sexual identity or sexual self, how they feel about themselves. That chemobrain, when we're having a hard time kind of clearing the cloud or feeling foggy, that when you're single and you're trying to date and you're trying to remember details of the last date you were on, or even when you're at work and just trying to reclaim some of that manhood or femalehood or feeling a little bit more like yourself, that when you can't completely be clear, there's less awareness or you're not as clear and you're feeling more hesitant to engage in intimate relationships. That has a huge impact on how you feel about your sexual self as well as your intimate relationships.

The hormone changes that chemotherapy causes are pretty significant. The majority of women experience hormone changes as well as men and I think sometimes we don't address it as much with men, but chemotherapy can affect hormone levels and disrupt them, menopausal symptoms for women, which include hot flashes, libido or desire changes, vaginal dryness and discomfort. There's the issue of changes in the vagina's integrity from chemotherapy, and erectile difficulties. Sometimes there's long-term peripheral neuropathy, which for someone who cannot get comfortable and has substantial tingling and irritation in their feet and hands, maybe being in a position where they are unclothed or engaging in sexual intimacy, it may be uncomfortable for them.

Chemotherapy also poses a threat to fertility and so infertility is possible.

There's also this idea of residual joint pain for some people, where chemotherapy has caused residual joint pain and it may be complicated by menopausal symptoms. So when you're experiencing joint pain, finding positions in a sexual

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BOLTE: relationship can be uncomfortable and challenging. Finding new positions is going to be important.

The cardiac and respiratory problems that can occur and stay. If you're having trouble breathing or catching your breath, that may make you less likely to want to engage in any kind of sexual relationship. Or even in your intimate relationships where you're just getting together with friends to go out for a walk, if you're having a hard time catching your breath, you may be less likely to engage in those kinds of activities.

And then for those of you on Gleevec® or thalidomide, we know that these drugs can pose a threat to conception. So if you are sexually active and using either of these drugs, you should be using protection. You need to talk to your oncologist about options if you are wanting to conceive a child and are on either of these drugs, whether you are male or female.

For those of you who have been through a transplant, we know that it presents a higher risk of infertility. The recent study published in 2007 in the *American Society of Hematology* found that men tend to have higher rates of sexual interest recovery than females; however, 40% of the men and 85% of the women reported problems that disrupted sexual function after 5 years. That's a pretty significant statistic to validate some of the concerns that many of you have had, that I've received in e-mails. We know that it should improve within 1 to 2 years after transplant, but testosterone levels and hormone levels may need to be checked and other enhancement aids may need to be used.

We do know that the vaginal depth can be affected for women after transplant, causing painful intercourse. Beyond just being put into a medical menopause as many women are from treatment themselves, you also may experience some vaginal changes. The depth of the vaginal area may have changed, which is important to identify with your gynecologist.

Challenging to reconnect after the fear of getting sick. There is this challenge of being concerned about connecting physically and sexually with your partner after transplant because you've been so impacted by the withdrawal and/or isolation that happened with transplant, but a lot of couples I work with, they're actually afraid to reconnect physically out of fear of getting sick again. Then there's been this emotional and physical withdrawal.

Some of the other problems that happen after treatment is that we're not only giving you chemotherapy, radiation, transplant, but then we're also giving you other medications to help you feel better. Such as some of the SSRIs [selective

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serotonin reuptake inhibitors] or other psychotropic medications we prescribe to help with mood, which can further interfere with desire and sexual response. So if you are on any psychotropic meds or SSRIs, it is important to speak to your healthcare team about options for either a different medication or dosage changes, or a medication that can be used in addition to the medications you're currently on, to help improve your sexual response.

Many physicians are very willing to talk about sexuality and intimacy and your concerns, but they may not be as apt to bring it up. So if it is impacting your quality of life, it's absolutely critical that you bring this up with your physicians.

The loss of libido that happens after treatment is both emotional and physical. There's this awareness or recognition of oh, my gosh, what just happened, when you've been diagnosed, with treatment, and you're done. And this feeling of wow, that just happened. A lot of people, as they try to make sense of that, start to feel overwhelmed, anxious. Some people may experience depression and depression complicates libido or desire. Then the physical part of libido that's affected is the hormone changes as well as fatigue, and some of the other late effects that you may experience from treatment.

The loss that happens from a cancer diagnosis that impacts sexuality and intimacy, one of them is fertility, feelings of sensuality, some of the role changes that occur. If you were the primary breadwinner or caretaker and that role was reversed when you were diagnosed, you may be struggling with how to redefine yourself within the context of your relationship. That's important to talk about with your partner or with your family members or your friends if you're talking about intimate relationships.

Sometimes treatments can also impact how we view ourselves, with the hair loss and the scars and the role changes that happen. So really taking care of looking at ourselves and taking good care of ourselves and reclaiming parts of ourselves is going to be really important.

The other quality of life issues that impact sexual function are anxiety, depression and nutrition. If we have poor nutrition, if we have high anxiety and we have high depression, those will all impact sexual function and as well as our intimate relationships. If you are smoking or using extensive alcohol, that can also cause erection difficulties and lack of interest.

So what do we do with that? We just covered a lot of what the treatments themselves can do. What can we do as survivors to really address and enhance our sexual self?



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Let's talk just briefly about fertility. Many of you on this call I'm sure are probably done with treatment, so if you have not started treatment or you're in the middle of treatment, I would highly recommend that you talk to your oncologist about what your fertility preservation options are, if there are any. We're still learning a lot about fertility after treatment. However, if you've completed treatment, it's important to discuss with your healthcare team your options.

Some of the options are adoption, if you are not able to conceive children on your own, or using a surrogate parent. *In vitro* fertilization may be a possibility for you. Or using a donor sperm or egg. You can talk to your oncologist and/or fertility specialist about this.

Remember that some people do recover their ability to have children, so it's important to continue to get your sperm count checked. I've had many young men who I've worked with who were told they were infertile and 7 years later they have a high sperm count and are able to conceive. So make sure you are talking to someone about getting the sperm checked.

As always, talk with your healthcare team about your desire to have children. Many providers recommend waiting 3 to 5 years post-diagnosis before trying to conceive. So talk to them ahead of time or start talking to them now about what your options may be. Again, if you are using a drug like Gleevec or thalidomide, there may be risks to conception. So even if it's not you that's taking it and you're the partner, one of you can put risk to that fetus, so you need to talk to your physician about your options.

Remember that just because you believe you may not be able to conceive, that doesn't mean that you can't get a sexually transmitted disease. I think I'm seeing this more with the younger patients I'm working with, that there's less awareness of the fact that even if you're infertile, it doesn't mean that you can't get other diseases. So you need to use protective sex if you're not in a monogamous relationship, even if you don't believe that you can conceive.

Some of the specific suggestions around performance. There were several e-mails around vaginal dryness and some of the libidic responses women are experiencing, as well as the erection difficulties that men are experiencing, so I want to touch on both of those.

For women the biggest complaints are vaginal dryness and libidic response, as I said. So some of the options for that are water-based artificial lubrications. I say water-based because they're usually the safest, they absorb nicely and they work

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well. Things like Astroglide®, Gyne-Moistrin®, K-Y® lubricant. There is also the option of using 100% Vitamin E oil. Ladies, you can use this on a daily basis. You would use it both internally and externally, so you would take the Vitamin E oil after you get out of the shower and you put your body lotion on, you would take the Vitamin E oil and apply it externally around the labia and clitoris as well as inside the vagina with a finger. That will help keep the membranes of the vagina moist and retaining some elasticity.

The problem with vaginal dryness is it's not always internal or external vaginal dryness. I think a lot of misconceptions are that vaginal dryness can be treated with just something like K-Y lubricants, and it doesn't always help with the internal discomfort that you're experiencing. So you need to look at other lubricants such as Replens® or other suppositories that are inserted and released over time, which will help with the internal vaginal dryness that you're experiencing.

You can also consider using heighteners or clitoral sensitivity agents. Web sites like [www.PureRomance.com](http://www.PureRomance.com) have several options and they're a safe place to shop. They have a survivorship component on it that will help. That just helps with increasing blood flow and sensitivity to the clitoral area, which helps with libidic response.

Using vibrators can also help with enhancing orgasmic as well as vaginal response or libidic response.

If you are having vaginal pain and discomfort with sex, you really need to talk to your doctor, your gynecologist or your oncologist, whoever you feel most comfortable with, about dilator therapy. Dilators are very easy to use and they can be used to help with decreasing anxiety around sexual intercourse or help with vaginal training. If you're having a hard time with climaxing, you can use the dilator to help strengthen the vaginal wall and to practice Kegel exercises, which I'll describe momentarily.

The other options, for those of you who do not have estrogen-receptive positive cancers, there are pieces out there or medicines out there like the Estring® ring or estradiol-releasing vaginal ring, or a testosterone patch may be an option. Using estrogen creams, other kinds of estrogen creams such as Premarin® or Vagifem® may be an option. So talk to your oncologist or your gynecologist about the options for estrogen creams or an estrogen ring. That can really help with keeping the vagina and the wall of the vagina's integrity thick because when you are put into a medical menopause or in a menopause or even just after chemotherapy,

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**BOLTE:** everything is very dry. What needs to happen is the membranes or the vaginal area need to stay moist and elastic.

There's also a product out there called the Eros-C which is available, I believe right now, only by prescription. It is similar to what a penis pump for men does, but it attaches to the clitoris, it's a small hand device, it can help with bringing blood flow down to the clitoris and help with clitoral stimulation as well as orgasmic response and libidic response. There have been very successful studies of the use of this device. So that may be something else that you explore and ask your physician about.

If you are experiencing vaginal pain, it is possible that the vaginal canal has shrunk and dilator therapy may be appropriate. You can use either a dildo or a vibrator as well. If you are not comfortable with the dilator therapy, then you need to consult your gynecologist or a physical therapist who specializes in pelvic floor exercises.

The other part, if you have had a transplant, in some women we've found, we are finding graft-versus-host disease in the vaginal area, which is causing painful sex and the loss of vaginal depth. That's to be evaluated by your gynecologist and your oncologist and is an important thing to be evaluated sooner than later, so that you can get the treatments and therapies that will help with preventing further pain and discomfort or further loss of depth.

For men, the biggest complaint, both in e-mails I received as well as questions that I got, around what about after cancer and sexuality, and it's really around changes in libido as well as changes in erectile function.

It's going to be important that you have your physician look at all of your medications, and this goes for both men and women. Have them look at your medications because many of the medications can impact erectile integrity like steroids and psychotropic meds. You can have your testosterone levels checked to see if possibly that may be impacting your erectile function and that's a fairly uncomplicated thing to do. You may be able to use a testosterone patch. You may need to change positioning or help your partner climax before you begin, if you're having a harder time maintaining an erection. Changing positions can help you feel more in control, it may help with insertion or feeling that you can maintain your erection longer, so you may need to get creative with some positions. If you're having a hard time with not being able to maintain an erection quick enough because you're finding yourself climaxing quickly, you may want to use a prolonging cream. The important thing about prolonging cream is you put it

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on and wait 5 to 10 minutes before you engage in sexual intercourse with your partner to avoid also desensitizing them.

There are devices that can help and have been extremely successful with men wanting to improve and maintain their erection. One of those is a penis pump or a penile pump, which can be bought online or your physician may be able to write a prescription for you to get that. There are penile injections or suppositories such as Muse® or Caverject®. Then there's the more aggressive form of fixing erection problems, which is a penile implant. This is done surgically. It is permanent. You do not lose sensation; your sensation is the same. However, it is a permanent procedure. You can also use penile rings to help maintain the erection. The one thing that's important about all of these is if you have low platelets, if you're on a blood thinner or if you're having trouble with blood clots, you really want to consult with your physician before using any of these devices, because you may be putting yourself at risk.

The medications that are out there for men such as Viagra®, Cialis® and Levitra®, are all good options for survivors, no matter what your age. But they are not all the be-all quick fix. They can't fix everything and it's not always effective for everyone, but it is a good thing to try if you are having a harder time with your libidic response and your erection. You can't use these medications if you have problems with your blood pressure, if you're on a blood pressure medication or you have heart concerns.

For both men and women, one of the things you can do to help enhance both orgasm and control is practicing Kegel exercises. That muscle, the pelvic muscle that I'm referring to that we work on with Kegel exercises, is the same muscle that you would use to stop urine flow. So how I usually recommend patients trying this is actually try and go to the bathroom and stopping the urine flow. Once you get familiar with what that muscle is, if you can spend time each day practicing tightening and holding it for 5 seconds and releasing, practicing tightening and releasing, again holding for 5 seconds, you will improve your body's ability to both have better control as well as higher orgasmic response.

The other thing you need to be aware of is the time of day, that the time of day that you may have been interested in engaging in any sexual practice with yourself or a partner may be different now after treatment. You may be exhausted by 9:00 when your normal routine with your partner was after the kids have been put to bed or after you'd watched your favorite TV show and it was later in the evening, and now you're feeling too exhausted to engage in that. So you may need to get creative around timing and either try practicing, engaging in

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BOLTE: intercourse or any kind of sexual activity in the morning or meeting for a lunch break, and make it fun and exciting and creative.

You may need to also get creative with positioning to help with enhancing response or control as I've mentioned before.

Also this may just require redefining your expectations as well as your partner's expectations. Sometimes we just aren't able to get back to the kind of function we had prior to cancer, but that doesn't mean it can't be good or better. It just means it's going to be different. So you can still have a very pleasurable sexual experience without an erection, you can still have a very pleasurable sexual experience without a high libidic response. You need to focus on touch, on sensation, on pleasurable feelings, the use of assistive devices for both partners that you may be able to use in your coupleship, using both forms of assistive devices.

You may need to use other forms of sexual stimulation such as mutual masturbation if you're not able to engage in intercourse. You may want to explore the idea of reading fantasy and erotica to one another. Whether you can or cannot have intercourse, this is a great way to stay connected. Then redefining sexual intimacy to include just being naked and cuddling, massage or other touch techniques.

To help enhance orgasm besides some of the things I've mentioned before, changing the expectation from a body thing to a mind thing. What I mean by that is oftentimes we rely on our body to tell us when we're excited or when we're going to be stimulated or excited by someone we're looking at or by ourselves when we're engaging in masturbation. We need to change our expectation from it being a physiological response first, to being a mind thing first. We need to give ourselves permission to take more time to be sexually stimulated or to be connected to our partner, we need to take more time to talk ourselves into being – our sexual enhancement. So when we are thinking that we want to engage sexually, give ourselves the whole day to think about that. Don't expect to come home after a long day's work, have to feed the kids or get the dog out for a walk, and then expect that you're going to have the desire to be sexually intimate. It's just not going to happen right away like that.

So if you plan on it, one of the things I recommend to couples I work with is set days. It does take the spontaneity out of it, but it also helps you with reconnecting and allows you to have the whole day to really work on getting yourself excited. You can send love notes to one another or practice, again,

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BOLTE: getting it back in your head, is imagining yourself being turned on, imagining yourself with your partner, so that your body has time to catch up to what your mind is telling it.

Using sensate focus exercises where you focus just on touch and the pressure of actual intercourse is taken off the table for a while. You can talk to a sex therapist about these exercises. Or go into some of the books that are out there like *Sex Matters for Women* or *The New Male Sexuality*. You can also look at the American Cancer Society's booklet, *Sexuality and Cancer*, they have written for both men and women.

You need to re-explore pleasurable body experiences alone. Do this in the bath on your own. I recommend that you get in the bath and you just begin with touching exercises on your own, so that you can guide your partner or yourself to what feels good, now that your body is starting to heal from treatment.

Some of the other questions I get is, "When do I disclose; How do I tell someone that I'm interested in that I had cancer?" I have no magic answer to this, but I can give you a few suggestions.

One is role play with a friend how you might disclose. Figure out what feels right to you, get comfortable telling your story in multiple settings. Maybe pick the number of dates at which you're going to disclose. One of my friends who's a survivor says by date four she tells people because she knows she's going to want dates five and six after date four, and that way she avoids the emotional hurt if that person chooses that they can't stay in the relationship.

You need to educate yourself on the implications of treatment on sexuality and fertility, so that when they ask questions you're able to answer them. Then maybe think about identifying intimate relationships in which you feel comfortable asking questions or sharing your story or showing your scars that you're concerned about.

The idea of body image changes and this feeling of, I'm not feeling attractive, is a hard one also to answer, especially on a teleconference, because everybody is so unique. But some of the things that you need to do to help with feeling attractive is just starting your day out with identifying negative thoughts and trying to replace them with positive thoughts and affirmations. If we wake up in the morning and the first thing we do when we look in the mirror is tell ourselves how awful we look, we're going to start believing that every day. So if we can

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wake up in the morning and look in the mirror and tell ourselves something positive, as simple as "I accept my body and I will do everything I can to love it and help it heal." Or, "today I will embrace what my body can do and I will help it heal in the process." Just something positive, focusing on that, or focusing on the things that haven't changed about yourself can help with that.

Celebrating the person you are and the body you have is going to be really important to your healing process.

If you're struggling with pain and fatigue in your sexual and intimate relationships, whether they are sexually involved or just intimate friendships, you need to plan for the time of day when your pain is weakest and you feel most refreshed. So schedule the time with your friends when you feel the best. This may mean they have to rearrange their schedule, but that's okay.

If you are going to be engaging in activity, whether sexual or not, if pain is an issue, make sure you take your pain medication a half hour to an hour prior to that activity. You can practice deep breathing or relaxation techniques, and remembering that exercise combats fatigue and helps relax and warm muscles. So whether that's walking with a friend or engaging in sexual intercourse with your partner, those are great exercises.

Some people have asked about this concern about if their partner isn't interested or the fear of rejection. It's hard to answer over a teleconference, but this is something I would absolutely encourage you to seek out if you are struggling in your partnership about wondering if your partner is struggling with how you look or how he feels or how she feels. Try to find a couples counselor or a sex therapist that's available to you to help you communicate about your needs. Remember, most of the time it isn't about you. A lot of times when I'm working with couples it's really about them having a miscommunication and one person being afraid that they're going to hurt the other, and them interpreting the information differently. So you need to communicate about your needs. Maybe there's an underlying fear or anxiety on their part.

Some of the ways you can do this is just through basic communication skills. The NCI [National Cancer Institute] puts out a great booklet, *Tips on Talking to Your Partner about Sexual Needs*. They talk about stating a fact, a belief, their feelings and then your needs.

So here's an example. You may start out by saying, "We've made love only a few times since my cancer treatment." That's a fact. Your belief is "I think it may be

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because my scars are a problem for you." And then your feelings, "When we don't have sex I feel very lonely and I miss being close to you and sometimes I always feel that cancer affects our sex life, too." And then your needs, "I would feel much better if we had sex more often and if it was your idea more often." So you're not just telling them what you're observing, a fact, and your belief about it as well as your feelings, but then you're giving them some concrete way to help fix it or to help with working with you on it. Because a lot of times in coupleships we're really good about talking about how we feel, but we don't give them tools on how they can respond better to help us feel better.

To start wrapping up on maintaining intimacy, one of the best things you can do for yourself is start with self-pleasuring exercises to get to know your body again and what makes you feel good. Your body has changed since treatment and so if you expect your partner to be comfortable with touching you or if you expect in the future a partner to be comfortable touching you, you need to be comfortable with touching yourself and knowing what does feel good and what doesn't feel good now. Remember that you can have an extremely sexual intimate relationship with your partner without the act of intercourse.

It's important to continue to reconnect with yourself. Just take time to take care of yourself. Whether that's going to a day spa, playing golf, going for a run, but take care of your physical self because the more you take care of your physical self, the better you're going to feel about yourself.

For the partner who's listening: communicate about your own desires. This is not selfish or insensitive. Be honest, focus on all other sensitive areas of your partner and don't be afraid to ask questions of your partner or the healthcare staff. Remember to show affection in a relaxed way, showing that you're still interested.

There are a lot of ways that we can stay connected with friends and families and as a couple. It goes back to communicating and asking for your needs to be met. Also avoiding toxic relationships. If you find that your intimate relationships are taking more energy out of you than they are giving you positive, then you really need to think about re-evaluating those relationships. That's an important part of reclaiming yourself as well as regaining intimacy in a healthy way.

Think back to when you first started dating if you're in a coupleship. Create essential mood. Go back to the lighting, the music, the scents. Taking the time to be together again, giving yourselves time to connect. Some people may say using teasing techniques where you're writing love notes or you start the morning off with giving him or her a kiss on the cheek or on the neck and telling them how



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BOLTE: beautiful they look and you can't wait to see them tonight. Starting it back to slow and easy and taking the pressure off sex if that's what has been a concern for you and just putting the focus back on getting connected.

Staying positive is going to be a very, very, very important part of staying connected.

To wrap up, you may need to find other ways to be sexual. Sometimes being naked is the most intimate experience you can have, that it's not just about sexual performance or sexual pleasure in that way, but maintaining sexual intimacy in the way that you can. If there are new limitations, like you can't maintain an erection, then find other ways for both of you to have pleasure. Go slowly at first. If you need to ask for more foreplay, you're going to have to learn to communicate about that need and ask for that need to be met.

You may also find that your social life has dramatically changed, so your intimate relationships have dramatically changed, so it's going to be really important that you find ways to connect with your friends or loved ones in a setting that you enjoy.

Remember that the appropriate timing of sex or activities in general may increase the enjoyment of them. You may need to get creative. You have control over who you surround yourself with. Remember that in evaluating your intimate relationships, you have control over who you surround yourself with.

Communicate about your needs, both to your partner as well as to your friends, as well as to your healthcare team, so that they can help you focus on regaining that high quality of life that you so deserve.

Remember that we can rest during sex. It's not a marathon. We're not in any rush to achieve anything and that's where redefining what our goals are with sex is going to be important. Remembering that it's not the only form of intimacy.

Patience and a sense of humor is an absolute must. We must be patient and laugh. Some of the changes that we experience after treatment are humorous at times. Some are frustrating, but if we can laugh and really enjoy just getting to know our bodies again, it will be that much better for us.

Finally, remember that skin is the largest sex organ and the brain is the most important sex organ, so the possibilities are truly limitless.

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BOLTE:

I want to end by a quote from the Mayo Clinic staff in 2003 saying "Intimacy need not end with cancer." You may need to redefine your way of expressing intimacy and you may need to experiment because what worked before may no longer work after cancer. But it need not end with cancer.

I know we've covered a lot of information and we've done it very quickly this afternoon. So I appreciate your patience on the phone call and I'll look forward to answering your questions. I also do want to let you know that my e-mail is available. The Leukemia & Lymphoma Society does have it, and I welcome you to e-mail me directly with more personal questions that you have or questions that I wasn't able to get to on the call.

So thank you again for your time this afternoon.

CARSON PATTILLO:

Thank you so much, Sage, for such a clear, informative, reassuring presentation, chock full of information. Our Information Resource Center has your e-mail address, so if anybody is requesting to contact you, for all of you to know on the phone, that if you call the Information Resource Center, we'll have Sage's contact information.

I'd also like to remind you, because Sage did mention some Web sites and some valuable resources, we will have the transcript and an audio archive in several weeks, so please watch out for that.

Also in your packet we included a list of materials that are available to you. One is our updated Fact Sheet on sexuality and intimacy. You can get that online. Just print the PDF off of the Web site or you can order it through the Information Resource Center. And actually Sage graciously reviewed that for us. So she was part of putting that together. So those are resources available to you.

Now, though, it is time for the interactive part of our program, the question-and-answer session. Before the operator gives instructions for all of you to enter the question-and-answer queue, I'd like to remind all of you that because we have over 1,000 participants on the line and for everyone to benefit, if you can please try to keep your question general in nature and Sage will provide an answer general in nature. Your phone line will be muted after you ask your question, so Sage can respond.

So Operator, please give the instructions to the participants so they can queue themselves for the questions.

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**OPERATOR:** To participate in the call by asking a question, please press star-1 on your keypad. We will take questions in the order they are received. Please be aware that due to time constraints, we can only take one question per person. Once your initial question has been voiced, the operator will transfer you back into the audience line. Again, to participate in the call by asking a question, please dial star-1 on your keypad.

**CARSON PATTILLO:** Thank you. Let's take our first question, please.

**OPERATOR:** Your first question comes from Andrea in New York.

**ANDREA:** Hi, actually this is her husband, Paul. We are parents of an adolescent who is a cancer survivor. I was hoping the speaker could address issues relating to sort of long-term psychological effects of a child who is undergoing chemotherapy at the same time that they are becoming aware of their sexuality.

**BOLTE:** That's a great question and I would love to speak to you off-call in greater detail about that because there's actually a lot of information coming out about that. But some of the key components of anyone who's been diagnosed as an adolescent, some of the risks are the stunted growth or under-development that takes place due to the treatments and it depends on the kind of treatment that your child has, that can affect how they feel. For some, especially girls, not having a period at the time that all of their other friends are having a period can impact how they see themselves as a developing young woman. It also may impact, just as they try to get to know their sexual self. It does stunt the process because they're immersed in a medical world that changes and somewhat sterilizes that environment for them.

So the best thing you can do as parents is encourage conversation with her about that. Ask her questions about how she's feeling, what does she have questions about, is she concerned about feeling or looking different. I worked with a young man not too long ago who was very concerned that he looked different than his other peers, and this was 7 years after he had been diagnosed with a brain tumor. He hadn't been willing to explore some of that with some of his peers. So I would encourage you to open conversation up with your daughter.

There are some long-term ramifications, both fertility as well as development, that can happen, depending on the treatment. But oftentimes what we see is that adolescents are extremely resilient, and although they may be a little behind emotionally and sexually because of treatment that kind of kept them back from engaging in the "normal" behaviors of teenagers, but they do catch up and they

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- BOLTE:** actually can develop into very healthy, well aware and sexually aware, confident young men and women.
- CARSON PATTILLO:** Excellent. Thank you for the question. Let's take another question, please.
- OPERATOR:** The next question comes from Jenny in North Carolina.
- JENNY:** My question is as a 65-year-old survivor of leukemia, when you suggest that there are creams for lubricating the vaginal area, I'm concerned. They're estrogen creams. There's been so many cases and so much history of women getting cancer in other parts of their body from additional estrogen. I wonder what your comments were about that.
- BOLTE:** That's a great question, Jenny, and a lot of women share your anxiety. One of the things I would encourage you to do is really weigh the risks and benefits with your oncologist or your gynecologist. But what we do know is the Estring, which is a ring that's placed internally in the vagina, is a localized estrogen treatment. It is not systemic estrogen. So none of the creams are systemic hormone replacements, which are associated with higher risk of cancer.
- Now because you do not have an estrogen-receptive kind of cancer, my guess is that your risks are low. But if you are concerned about that at all, if the anxiety is going to be higher for you to use those creams than it would be to use something else, then I would absolutely recommend using some of the more internal lubricants like Replens or some of the other suppositories that also help with the internal vaginal dryness that women can experience.
- But the risks we are seeing are fairly low for women who are postmenopausal and are not taking hormone replacement, but just using localized low dose – and they are very, very low-dose estrogen creams. There may be some other ones that are progesterone or others that are good options for you that may not impact your own anxiety around the concern of having a secondary cancer related to the estrogen.
- Great question, Jenny.
- CARSON PATTILLO:** Jenny, thank you for the question. Let's take another question, please.
- OPERATOR:** The next question is from Edlanda in Michigan.

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- EDLANDA: Hello, thank you for taking my question. I have a two-part question, I'll make it really quick. You talked about using the Vitamin E oil as a lubricant and I just wanted to know for some of my clients that may be practicing sex with a condom, does the oil in the Vitamin E, is it latex-friendly or should they use a polyurethane condom? And then could you spell the Eros-C, that you were talking about, the clitoral pump?
- BOLTE: Absolutely. I'll start with the Eros-C. As for Vitamin E oil, from my knowledge it's not going to strip the protectiveness of a latex condom. My understanding is it is latex-friendly. That is a great question, though. If they are comfortable using a polyurethane condom, then they may want to do so. From experience, though, Vitamin E oil, what I recommend is using that more for the female, not with sex, but actually after.
- So let me clarify because that actually brings up a great clarification. When a woman is using Vitamin E, the way I recommend it is using it as a body lotion. So every day when you get out of the shower you put your Vitamin E oil on just as you do for your body. It will be sticky to use as an actual lubrication for sex. So I would recommend using the Vitamin E oil in the morning after a shower or in the evening after a shower, and then using an additional external lubricant such as Astroglide or Wet® or the others that are out there that are water-based for sexual – for any kind of penetrative sex.
- CARSON PATTILLO: Thank you for the question.
- Sage, I have a question for you and as elementary as it sounds, if you could just address the issue of blood cancers and if they are contagious or not, and if they can be transmitted during sexual intercourse. We get that question actually frequently into our Information Resource Center. So the difference between sexually transmitted diseases and transmitting the cancer.
- BOLTE: What we know is that all of the blood cancers and really any cancers other than some of them that are virus-based are not transmissible during sex. It is not possible to transmit them with oral sex, with kissing, with bodily fluids at all. That they are not transmittable. So any kind of sexual engagement that you engage in, you're not going to be concerned about doing that. It's different than having HIV; that's a blood disease. The blood cancers are not transmittable through any kind of sexual engagement.

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- CARSON PATTILLO: Thank you. Let's take another question, please, from the telephone audience.
- OPERATOR: The next question comes from Elnora in Mississippi.
- ELNORA: My name is Elnora and I was diagnosed with AML [acute myelogenous leukemia] in 2005. My question is, what do you do to get your husband or mate to pay you any attention and is weight gain – you know, I gained a lot of weight since I've had the leukemia, and I wonder if that's making me unattractive to him.
- BOLTE: That is a great question and I hear that a lot from women, that they feel if their partner has withdrawn sexually, that it's about the way they look. Oftentimes I've heard from their male partners it has nothing to do with the way they look, it's more about they're afraid that they're going to either hurt the woman because the woman had pain or they're afraid that they don't want to be pushy, they don't want to be perceived as being selfish, that they are asking for sex after this, that they want to give you time to rest and recuperate. Sometimes it's just a routine that couples have gotten into it. After a year of treatment and not having sex, some couples just set into a routine and those routines are hard to break. He may interpret that sex isn't important to you.
- But the biggest thing you can do is open that door of communication, Elnora, that you ask him what he's thinking. Is it that he's not attracted to you and just ask him, use the statements that I talked about earlier, where you state a fact, your belief, your feelings and then what you need him to do different. If it's that he's feeling either less attracted to you or maybe he has his own issues, then I would highly recommend you talking to a couples counselor or a sex therapist who can get you back into touching and reconnecting.
- There are also some great books out there that you may find on [Amazon.com](http://Amazon.com) or go to your local library, that are good books on couples redefining intimacy and sexuality after cancer, that may be helpful to you.
- But the best thing you can do, Elnora, is just initiate the conversation. You can do it very easily. You have the excuse of listening to the teleconference and going to him and saying, "You know, I was listening to this teleconference and I'm wondering if you're feeling like we can't have sex any more, I'm wondering if my weight is a problem for you." And ask the questions.
- The other thing you can do is try to get his attention by doing things that are more attention-seeking. So that may mean that you wear sexy lingerie or you light candles or you see things that maybe may turn him on to get his attention and show him that you're trying to get his attention.

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**BOLTE:** There's no quick fix for this, but I'd try the baby steps towards just communicating and some of the things you can do to help him know that you actually do want to engage in some sexual intimacy.

**CARSON PATTILLO:** Elnora, thank you so much for participating today and the question. Let's take the next question, please.

**OPERATOR:** The next question comes from Patty in Missouri.

**PATTY:** Thank you for taking my question. Do postmenopausal women who receive R-CHOP [rituximab, cyclophosphamide, doxorubicin, vincristine, and prednisone] still have some ovarian function, ie, some estrogen production, however diminished by age, that is equal to that of an untreated postmenopausal woman of the same age? Or is postmenopausal ovarian function stopped completely and permanently by the R-CHOP?

**BOLTE:** That is a great question and it really varies from woman to woman. There's no general answer to that. It varies on the woman, what age they were before, whether they were fully menopausal, there's a lot of things that go into it. So the estrogen function varies. But your androgen levels or your pituitary gland also help with hormone levels, so although there may be hormone deficiency, there are other parts of your body that are helping with that as well. So if you're wondering about where your hormone levels are at, I would talk to an endocrinologist or your gynecologist and have them do a thorough run-up and see where you're at, because it does vary from person to person. Great question, Patty. It's complicated, but a great question.

**CARSON PATTILLO:** Patty, thank you for the question. And thank you all for your questions. Our 1-hour program has come to a close. If you can please all help me thank Sage for being with us today. We're so grateful that she's donated her time.

And we hope that many of your questions were answered and that the information today will assist you in your next steps.

And a reminder to all of you to fill out your program evaluation. Or if you're a nurse or social worker, to fill out your continuing education credit form. You can return it in the envelope provided, but we also encourage you to complete the evaluation online, and that Web address again is [www.LLS.org/eval](http://www.LLS.org/eval). Nurses and social workers must enter the code SURV for survivorship, SURV575B.

And a reminder to all of you that our Information Resource Center is open.

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CARSON PATTILLO: Do not hesitate to contact us if you have further questions. Our master's level information specialists are available to provide you with more information and can link you with your local chapter. Also we do have Sage's contact information if you choose to contact her at a later time. The Information Resource Center number again is 1-800-955-4572.

So on behalf of The Leukemia & Lymphoma Society and Sage, I'd like to thank you all for sharing this hour with us. We wish you well. Good-bye.

OPERATOR: This concludes today's conference call. You may now disconnect.

END