

Human beings have the natural desire to be touched, hugged, caressed and loved. Whether this is fulfilled in a partnership or by close friendships, most people desire close relationships that involve intimacy at some level. Sexuality and intimacy are not life or death issues—but are very real quality of life issues. Oftentimes I hear people say, “This [sex] should be the last thing on my mind in the midst of all the other things in my life.” Or a partner says, “It’s selfish of me to be concerned about sex.” – Sage Bolte, PhD, LCSW, OSW-C, CST, Oncology Therapist

A blood cancer diagnosis (leukemia, lymphoma, myeloma, myelodysplastic syndromes or myeloproliferative neoplasms) may affect you in a number of different ways. One concern you may have is how the disease and treatment will affect your current or future relationships, including effects on your sexuality.

Sexuality encompasses physical, psychological, social, emotional and spiritual factors. It includes self image, body image, reproductive ability, emotional intimacy, sensual feelings and sexual functioning. Discussing sexuality-related concerns may be important to your quality of life in areas that are not limited to sexual functioning, such as feeling comfortable with yourself and enjoying intimate connections with loved ones.

Sexual health and sexuality are important regardless of your relationship status. Your sexuality is an integral part of who you are, how you express yourself and how you feel about yourself. It is important to understand the sexual changes that are possible both for your ongoing sexual health but also should you ever enter into a new relationship. Additionally, your sexuality is important even if you are not sexually active. Your sexuality helps you maintain a positive body image and feelings of confidence whether you are in a relationship or not.

This fact sheet provides information about how your disease and treatment may affect your sexuality and intimate relationships, along with suggestions for communicating with healthcare professionals, partners and friends. You may also want to read the LLS free booklet, *Fertility Facts*.

Cancer and Sexuality

Sexuality-related concerns may arise from the physical aspects of your disease or treatment, as well as from the emotional aspects. Anger, guilt, or worry—about illness and survival, treatment or even finances—may affect sexuality. Some physical or emotional effects resolve over time or when treatment ends. Other effects may be long-lasting. And some may not appear until two or more years after treatment.

Some Ways that Cancer or Cancer-Treatment Affect Sexuality

- You may have a different sense of self-worth and self-confidence than you did before being diagnosed with cancer.
- You may feel depressed, anxious or have little or no interest in sex.
- You may feel embarrassed or worry that others see you differently because of physical changes such as weight gain or loss, hair loss, swelling, scars or the presence of a central line or port.
- You may have few chances to be alone or intimate with your partner because of hospitalizations or treatment schedules.
- Survivors of childhood cancer may be self-conscious about underdevelopment or delayed development.
- You may have different sexual priorities or expectations during treatment and when treatment ends.
- Your partner may have different sexual priorities or expectations during treatment and when treatment ends.
- You may have low energy or fatigue that interferes with all intimate activities.
- Side effects of treatment, such as peripheral neuropathy or graft-versus-host disease, may make your skin sensitive or uncomfortable.
- Pain, nausea or vomiting, problems with erection or premature ejaculation or vaginal dryness or discomfort during intercourse may interfere with your ability to be interested in or enjoy sex.
- Your oncology team may advise you to abstain from intercourse for a period of time if your total white blood cell count and/or your platelet count are below a certain number, or for other medical reasons.

Healthcare and Sexuality

Sexuality and intimacy are often overlooked topics of discussion within healthcare settings. Oncologists do not always offer information about sexuality to their patients. If you have not received any information from your doctor or other healthcare team members, it is not because sexuality and intimacy are not important to them or to you. You may need to bring up the topic and ask your questions you—know that help is available.

Some Questions to Ask Your Healthcare Providers

- Will my treatment affect my ability to have sex? If it will, how long will this effect last?
- Is it safe for me to have sex during the period of time that I am in treatment?
- Will my illness or treatment affect my ability to become pregnant (or father a child)?
- Who else can I speak with about this topic? Are there counselors, sex therapists, support groups or other support services in my area?
- (For hospitalized patients) Can you help me arrange for some private time with my partner as long as it does not interfere with my medical care?
- What do I need to know about birth control and protection from sexually transmitted infections (STIs)?

Note that it is important to use barrier protection (condoms or dental dams) during intercourse or oral sex to protect you and your partner from STIs or from possible exposure to residues of chemotherapies that may be present in semen or in the vagina. For people of childbearing age, birth control is important because certain cancer treatments can harm an unborn child. For some treatments, doctors may advise patients to use birth control for up to one year after treatment ends. Ask your healthcare team for more information.

To help you talk with your healthcare providers, you may want to

- Bring your partner to your next visit with your doctor, nurse or social worker/counselor. Give your partner a chance to ask any questions he or she may have. This can be done individually or together.
- Ask your doctor, nurse or counselor to use models or drawings to help convey information.
- Ask if you can record the questions and answers. By recording what your doctor, nurse or counselor says, you will be able to replay the information as many times as you need later on.
- Keep a journal or notebook of questions to ask your doctor, nurse or counselor at your next visit. Leave space for answers so that you can refer to them afterward.

- Ask your doctor, nurse or counselor if he or she communicates with patients by email or has a Web site with information for patients.

Members of your oncology team can give you referrals to other healthcare professionals that may be helpful depending on your situation. These healthcare professionals include

- Gynecologist
- Urologist
- Endocrinologist
- Fertility doctor
- Pelvic floor therapist
- Oncology social worker
- Certified sex therapist.

You may want to get information from support organizations about maintaining intimacy in your relationships and/or ways you can feel more attractive. You may find value in talking with cancer survivors about how to deal with self-image issues and other aspects of sexuality. You may also find it helpful to talk with a good friend, a family member or a spiritual advisor about how you feel.

Communicating with Your Partner

Discussing experiences, feelings and concerns with your partner—giving each other the chance to talk and listen—may be an important part of maintaining or improving your quality of life and your intimate relationships. Your partner may have his or her own concerns, such as being afraid of hurting you during sex, feeling guilty or selfish for wanting to be intimate with you, or not knowing how to talk about his or her feelings. You may want to talk about seeking help from a professional, such as a couple's counselor.

If sexual intercourse is important to you, but one or both partners is having difficulties with sexual desire or performance, consult with your doctor to rule out any physiological problems. A sex therapist can assist in solving certain difficulties. The American Association for Sexuality Educators, Counselors and Therapists at www.aasect.org can help you locate a therapist (click on "Locate a Professional") or you can ask your healthcare team for a referral.

An intimate relationship does not have to include sexual intercourse. You and your partner may want to set aside more time to spend together, to communicate openly and to enjoy other ways of physical closeness—touching, kissing, cuddling, holding hands, giving each other a massage or taking a walk together.

Suggestions for Coping with Cancer or Cancer-Treatment Effects on Sexuality

- Write love notes or simple messages in an email, text message or on a sticky note to remind your partner how much you love and appreciate him or her.
- If needed, take medication for pain or nausea 30 to 60 minutes before sexual activity. Some of the medications prescribed for nausea and pain may interfere with sexual performance. Ask your oncology team about side effects, and, if needed, possible alternatives or dosing options.
- Some treatments may cause vaginal dryness. Talk with your oncology team about using vaginal lubricants, moisturizers or other aids to make intercourse more comfortable.
- Some treatments may cause erectile dysfunction. Talk with your oncology team about your options or a referral to an expert.
- Take a warm shower or bath to help relax your body.
- Take a nap before intercourse to help you feel less tired.
- Set the mood. For example, light candles and play music.
- Take your time—appreciate and enjoy each other and the gift of being able to be fully open and intimate with one another.
- You may not be interested in sex. It is also common for people to have problems with sex during cancer treatment. Until your treatment is completed and you feel better, you and your partner may need to find new ways to be intimate.

For the Single Person and/or New Relationships

Your sexual health and sexuality are important whether or not you are in a relationship. If you are in a new relationship or are planning to start dating, you may be wondering how to tell someone that you have/had cancer. Before you begin dating, consider any physical changes, or changes in the way you perceive yourself, both positive and negative, since your cancer diagnosis. It is certainly possible your priorities and desires have changed since your diagnosis. If you are uncomfortable with any changes in your body, spend time reconnecting to your body and finding things about yourself that you appreciate. Talk to an oncology social worker or counselor if you find that you are struggling with how to reconnect to yourself, or if your emotions are interfering with your view of your sexual self.

One way to get comfortable telling your story is to role play with a friend. Act as though you were on a date and wanted to disclose your cancer story. It may also help to

- Share your story at your own pace—there is no right or wrong time to tell or not to tell. However, disclosure should probably happen before there is a close emotional attachment. If the other person is uncomfortable about you being a survivor, there will be less heartache or conflict.
- Take advantage of survivorship conferences and camps to connect with other cancer survivors and hear their stories. Support groups are another great resource and place to connect.
- Be positive and find laughter in your life.
- Tell your friends about your worries or fears so you have people to encourage you.
- Talk to a social worker or counselor about your concerns.
- Have people in your life that are supportive and help you maintain a positive self view.

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We're Here to Help

LLS is the world's largest voluntary health organization dedicated to funding blood cancer research, education and patient services. LLS has chapters throughout the United States and in Canada. To find the chapter nearest to you, visit our Web site at www.LLS.org or contact

The Leukemia & Lymphoma Society

3 International Drive, Suite 200
Rye Brook, NY 10573
Contact an Information Specialist at (800) 955-4572
Email: infocenter@LLS.org

LLS offers free information and services for patients and families touched by blood cancers. The following lists various resources available to you. Use this information to learn more, to ask questions, and to make the most of your healthcare team.

Consult with an Information Specialist. Information Specialists are master's level oncology social workers, nurses and health educators. They can answer general questions about diagnosis and treatment options, offer guidance and support and assist with clinical-trials searches. Language services are available. For more information, please:

- Call: (800) 955-4572 (M-F, 9 a.m. to 9 p.m. EST)
- Email: infocenter@LLS.org
- Live chat: www.LLS.org
- Visit: www.LLS.org/information specialists

Free Materials. LLS offers free education and support booklets that can either be read online or downloaded. Free print versions can be ordered. For more information, please visit www.LLS.org/booklets.

Telephone/Web Education Programs. LLS offers free telephone/Web education programs for patients, caregivers and healthcare professionals. For more information, please visit www.LLS.org/programs.

Co-Pay Assistance Program. LLS offers insurance premium and medication co-pay assistance for certain eligible patients. For more information, please:

- Call: (877) 557-2672
- Visit: www.LLS.org/copay

Online Blood Cancer Discussion Boards and Chats. Online discussion boards and moderated online chats can help cancer patients reach out, share information and provide support. For more information, please visit www.LLS.org/getinfo.

LLS Community. LLS Community is an online social network and registry for patients, caregivers, and supporters of those with blood cancer. It is a place to ask questions, get informed, share your experience, and connect with others. To join visit communityview.LLS.org.

LLS Chapters. LLS offers support and services in the United States and Canada including The *Patti Robinson Kaufmann First Connection Program* (a peer-to-peer support program), in-person support groups, and other great resources. For more information about these programs or to contact your chapter, please:

- Call: (800) 955-4572
- Visit: www.LLS.org/chapterfind

Clinical Trials (Research Studies). New treatments for patients are under way. Many are part of clinical trials. Patients can learn about clinical trials and how to access them. For more information, please:

- Call: (800) 955-4572 to speak with an LLS Information Specialist who can help conduct clinical-trial searches
- Visit: www.LLS.org/clinicaltrials

Advocacy. The LLS Office of Public Policy (OPP) enlists volunteers to advocate for policies and laws to speed new treatments and improve access to quality medical care. For more information, please:

- Call: (800) 955-4572
- Visit: www.LLS.org/advocacy

Resources

American Association of Sexuality Educators, Counselors and Therapists

(202) 449-1099

www.aasect.org

Assists patients in finding a professional sex therapist or counselor in their area; provides professional education; and conducts sex education research.

American Society for Reproductive Medicine

(205) 978-5000

www.asrm.org

Provides information on reproductive medicine, including infertility, menopause and sexuality. Patient and professional sites are available on its Web site.

CancerCare

(800) 813-4673

www.cancer care.org

Provides counseling, support groups, educational workshops and publications.

Cancer Hope Network

(877) 467-3638

www.cancerhopenetwork.org

Provides support, information and hope to people with cancer and their families.

Livestrong Fertility

(855) 220-7777

www.livestrong.org/we-can-help/fertility-services

Provides information and resources on reproductive issues and support for cancer patients. Provides a discount program to help cancer survivors obtain discounted rates on fertility preservation services.

Path2Parenthood

(888) 917-3777

www.path2parenthood.org

Provides information on infertility treatment, reproductive health, family planning, sexuality, and adoption. Provides a find a professional search tool.

RESOLVE: The National Infertility Association

(703) 556-7172

www.resolve.org

Promotes reproductive health for persons experiencing infertility or other reproductive disorders. Provides support programs across the United States.

Section on Women's Health

(703) 610-0224

www.womenshealthapta.org

Patients can use the locator to find a physical therapist that specializes in pelvic floor health.

Stupid Cancer

(877) 735-4673

www.stupidcancer.org

Provides information and promotes cancer education, advocacy, research resources and support for young adults with cancer.

References

Katz A. Men cancer sex. Oncology Nursing Society. 169 pages.

Katz A. Women cancer sex. Oncology Nursing Society. 176 pages.

Schover LR, van der Kaaij M, van Dorst E, et al. Sexual dysfunction and infertility as late effects of cancer treatment. *EJC Supplement*. 2014; 12(1); 41-53.

Shapiro D. And in health: a guide for couples facing cancer together. Penguin Random House. 240 pages.

World Health Organization. Sexual health. Available at: http://www.who.int/topics/sexual_health/en/. Accessed March, 2016.

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