

Sexuality and Intimacy

No. 11 in a series providing the latest information for patients, caregivers and healthcare professionals

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, ABD, LCSW, OSW-C, Oncology Counselor

A blood cancer diagnosis (leukemia, lymphoma, myeloma, myelodysplastic syndromes or myeloproliferative disorders) 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 sexuality.

Sexuality refers to 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 close communication with loved ones.

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 fact sheet, *Fertility Facts*.

Cancer and Sexuality

Sexuality-related concerns may arise from the physical aspects of your disease or treatment, as well as from emotional aspects. Anger, guilt, or worry—about illness and survival, treatment or finances—may affect sexuality. Some physical or emotional effects resolve over time or when treatment ends. Other effects may be long-lasting.

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 or 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 hospitalization or treatment schedules.
- Survivors of childhood cancer may be self-conscious about underdevelopment or delayed development.
- Side effects of treatment, such as peripheral neuropathy or graft versus host disease, may make your skin sensitive or uncomfortable. Fatigue, pain, nausea or vomiting, problems with erection or premature ejaculation, 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 is below 1,000 and/or your platelet count is below 20,000, 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 physician, it is not because sexuality and intimacy are not important. You may need to bring up the topic and ask any questions you have—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'm in treatment?
- Will my illness or treatment affect my ability to become pregnant (or father a child)?
- Where can I get information about fertility and family planning options?
- Where can I get information about nutrition, exercise and skin care?
- 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, physicians 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 physician or counselor. Give your partner a chance to ask any questions he or she may have.
- Ask your physician or counselor to use models or drawings to help convey information.
- Ask if you can record the questions and answers. By recording what your physician 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 physician or counselor at your next visit. Leave space for answers so that you can refer to them afterward.
- Ask your physician 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. A consultation with a gynecologist, urologist or family physician, an oncology social worker or a certified sex therapist may be helpful, depending on your situation. You may want to get information from support organizations, including information about maintaining intimacy in your relationships and/or ways you can feel more attractive. You may find value in talking with cancer survivors to find out how they are dealing with self-image issues and other aspects of their 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. 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 couples counselor.

If sexual intercourse is important to you, but one or both partners is having difficulties with sexual desire or performance, consult with your physician to rule out any physiological problems. A sex therapist can assist in solving certain difficulties. The American Association for Sex Educators, Counselors and Therapists at www.aasect.org can help you locate a therapist (click on “For the Public” and “Locate a Professional”) or you can ask your physician 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 to experience 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 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 intending to be sexually intimate. 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 lubricants or other aids to make intercourse more comfortable.
- 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, but still feel “obligated” to have sex. Talking with your partner about what each of you wants and how each of you feels can help you understand each other better. You may want to speak with an oncology social worker or counselor, either by yourself or as a couple.

New Relationships

If you are in a new relationship or are planning to start dating, you may be wondering how to tell someone that you have cancer. Before you begin dating, consider any physical changes, or changes in the way you perceive yourself, both positive and negative, since the cancer 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.

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 survivors and hear their stories.
- Be positive and find laughter in your life.
- Tell your friends(s) about your worries or fears so you have someone to encourage you.
- Talk to a social worker or counselor about your concerns.

We're Here to Help

The Leukemia & Lymphoma Society (LLS) is the world's largest voluntary health organization dedicated to funding blood cancer research, education and patient services. LLS has chapters throughout the country and in Canada. To find the chapter nearest you, visit our Web site, www.LLS.org, or contact

The Leukemia & Lymphoma Society

1311 Mamaroneck Ave.

White Plains, NY 10605

Information Resource Center: (800) 955-4572

Email: infocenter@LLS.org

Callers to the Information Resource Center may speak directly with an information specialist, Monday-Friday, 9am-6pm, ET. You may also contact an information specialist by clicking on Live Help (10am-5pm) at www.LLS.org or by sending an email. Information specialists can answer general questions about diagnosis and treatment options, offer guidance and support, and assist with clinical trial searches for leukemia, lymphoma, myeloma, myelodysplastic syndromes and myeloproliferative disorders.

The LLS Web site has information about how to find a clinical trial, including a link to the clinical trials search service of the National Cancer Institute. LLS provides fact sheets and booklets that can be ordered via the 800 number or through the Free Materials on the Web site.

Other national organizations:

American Association of Sexuality Educators, Counselors, and Therapists

(804) 752-0026 www.aasect.org

Provides professional education and conducts sex education research.

American Fertility Association

(888) 917-3777 www.theafa.org

Provides information on infertility treatment, reproduction and sexuality, and adoption.

American Society for Reproductive Medicine

(205) 978-5000 www.asrm.org

Provides information on reproductive medicine, including infertility, menopause and sexuality.

Cancer Hope Network

(877) 467-3638 www.cancerhopenetwork.org

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

Fertile Hope

(866) 965-7205 www.fertilehope.org

Provides information on reproductive issues and support for cancer patients.

I'm Too Young For This

(877) 735-4673 i2y.com

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

International Premature Ovarian Failure Association

(703) 913-4787 www.pofsupport.org

Provides community, support and information about premature ovarian failure.

LIVESTRONG/The Lance Armstrong Foundation

(866) 673-7205 www.livestrong.org

Provides practical information and tools through advocacy, public health and research.

People Living With Cancer

(888) 651-3038 www.cancer.net

Provides oncologist-approved information for individuals and families.

Planet Cancer

(512) 452-9010 www.planetcancer.org

Provides community, information and support for young adults with cancer.

RESOLVE: The National Infertility Association

(703) 556-7172 www.resolve.org

Promotes reproductive health for persons experiencing infertility or other reproductive disorders.

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