

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

This fact sheet covers a range of sensitive topics related to intercourse, sexual health, intimacy and cancer. Although not always discussed, sexual health and intimacy are an important part of your wellbeing, even after a cancer diagnosis. Please note: If you have experienced any type of sexual trauma, we recommend that you seek support and help from a trusted healthcare professional before reading further.

Highlights

- Sexuality and intimacy are important aspects of quality of life. Your sexual self is an important part of who you are.
- Cancer and cancer treatment(s) can affect sexual health and intimate relationships in physical and emotional ways.
- Cancer treatment(s) can cause sexual side effects such as decreased desire, erectile disorder, vaginal dryness and pain. There are many ways to address these changes.
- Sex or sexual activities may not be safe during treatment if white blood cell or platelet counts are low due to risk of infection or bleeding.
- Being immunocompromised can increase exposure to sexually transmitted infections (STIs). Use barrier methods, such as condoms or dental dams, to prevent STIs.
- Getting pregnant during cancer treatment could be unsafe for the pregnant person and fetus. Use a form of birth control during cancer treatment. Discuss what form of birth control is best for you with members of your healthcare team.
- Healthcare professionals, including specialists such as gynecologists, pelvic floor therapists, endocrinologists, urologists and sex therapists, can help patients address issues related to sexual health and intimate relationships.

“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.” Yet sexual health, just like many other aspects of health is an important part of a person’s life during and after a cancer diagnosis.”

— Sage Bolte, PhD, LCSW, CST

Introduction

Blood cancer and its treatments can directly and indirectly affect your sexual health and intimate relationships. Your sexuality encompasses physical, psychological, social, emotional and spiritual factors. It includes self-image, body image, fertility, emotional intimacy, sensual feelings and sexual functioning.

Sexual health and sexuality are important regardless of your relationship status. Your sexual health is important even if you are not sexually active. 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 potential changes that may affect your ongoing sexual health as well as your current or future relationships.

Cancer treatment can affect fertility (the ability to have a biological child). For more information, visit www.LLS.org/booklets to view *Fertility and Cancer Facts*.

Cancer and Sexuality

Sexuality-related concerns may arise from the physical aspects of blood cancer and/or its treatment, as well as from the emotional aspects. Some physical or emotional effects resolve over time or when treatment ends. Other effects may be long-lasting. Some may not appear until years after treatment has been completed.

Cancer and/or its treatment may affect your sexuality and/or your sexual health in many ways, for example:

- You may have a different sense of self-worth and self-confidence than you did before being diagnosed with cancer—you may find that you have either a more positive or a more negative sense of self.
- You may have a different relationship with your body than you did before your diagnosis. Your feelings toward your body may change as you move through or finish treatment.
 - You may feel a sense of anger or betrayal.
 - You may feel more aware of or more in tune with your body.
 - You may find a new appreciation for what your body can do.

- You may feel depressed, anxious and have little or no interest in sex.
- You may feel self-conscious or worry that others see you differently because of physical changes such as weight gain or loss, hair loss, swelling, scars and/or the presence of a central line or port.
- You may notice skin changes including rashes, bruising, dark or light patches, dry or peeling skin and brittle nails.
- You may find few opportunities to be alone with or intimate with your partner because of hospitalizations or treatment schedules.
- Survivors of childhood cancer may become self-conscious if they experience delayed puberty. They may develop the physical changes associated with puberty more slowly than their peers, or they may not have started to develop them at all.
- Your sexual priorities may change during treatment or when treatment ends.
- Your partner's sexual priorities or expectations may change during your treatment or when your treatment ends.
- Your partner may be concerned about approaching you intimately and worry about how that might impact your treatment, cause you to feel pressure or pain, or hurt you in some way. Open and honest communication is critical for both of you at this time in your relationship.
- You may have low energy levels or experience fatigue that interferes with sexual or intimate activities.
- Treatment side effects, such as pain, nausea, and/or vomiting, may interfere with your interest in or enjoyment of sex or intimate activities.
- Some cancer treatments may cause sexual side effects, such as decreased desire, changes in erectile function or vaginal changes such as vaginal dryness and pain.
- Your treatment team may advise you to abstain from intercourse (vaginal or anal) or other sexual activities if your white blood cell (WBC) counts are low. Sexual activity can introduce bacteria into the body that could lead to infection. White blood cells fight infection, so you are more likely to develop infections when your WBC counts are low.
- Your treatment team may also advise you to abstain from intercourse (vaginal or anal) or other sexual activities if your platelet count is low. Platelets help slow or stop bleeding. You may be at risk for excessive bleeding or bruising if your platelet counts are low.

- Chemotherapy drugs can be present in bodily fluids including, saliva, semen and vaginal fluids for up to 48-72 hours depending on the drug. The risks of exposure to chemotherapy drugs or other medications during sexual activity are not clear. Ask your treatment team if you should take any precautions or avoid sexual activities for some time after treatment to protect your partner from exposure.

Healthcare and Sexuality

Sexuality and intimacy are often overlooked topics of discussion within healthcare settings. If you have not received any information from members of your healthcare team, you may need to bring up the topic with a trusted healthcare professional and ask questions. Know that your sexual wellbeing is important, and help is available.

Members of your treatment team can also refer you to other healthcare professionals who may be helpful depending on your situation, including a:

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

Some Questions to Ask Members of Your Healthcare Team

- 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?
- What do I need to know about birth control?
- What do I need to know about protection from sexually transmitted infections (STIs)?
- Will my diagnosis or treatment affect my fertility (ability to have biological children)?
- Will my treatment cause medically induced menopause? If so, how does this impact sexual functioning? What can I do to address this?
- What are some options to prevent or prepare for sexual health concerns during treatment?
- How can my partner and I both be proactive in optimizing my/our sexual health while undergoing treatments?

- I have noticed my erections are not as firm, what can I do to address this? Would medication or supplements help and be safe for me?
- I have noticed increased vaginal dryness and discomfort, what is available to help?
- Who else can I speak with about this topic? Are there counselors, sex therapists, support groups or other support services in my area?
- Now that I am hospitalized, can you help me arrange for some private time with my partner, providing it does not interfere with my medical care?

To help you communicate effectively when you are talking with members of your healthcare team, you may want to:

- Use a journal or notebook and keep a running list of questions that come up and that you will want to ask your doctor, nurse or therapist at your next visit. Leave space for answers so that you can refer to them afterward.
- You may want to speak to members of your healthcare team without your partner, family member, friend or parent being in the room. Before an appointment, you could even send a note to a member of your healthcare team telling them you would like to speak privately.
- Ask if you can audio-record the questions and answers on your phone. This way you will be able to replay the information as many times as you need. If no audio recording is allowed, ask for relevant printed information so that you can review that later.
- Ask your doctor, nurse or therapist to show you models, images, or to draw simple diagrams that will help to convey information visually.
- Bring your partner to your next appointment. Give your partner a chance to ask any questions they may have. This can be done either individually or together.
- Ask where you can find additional information and resources online.
- Ask about local and/or online support groups.

You may want to get information from support organizations about maintaining intimacy in your relationships and/or ways to help you feel more comfortable with your body. 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.

Disclosing Sexual History and/or Sexual Orientation.

When discussing sexual health, your healthcare team may ask about your sexual history such as current sexual activities, the sex and/or gender of your partner(s), previous/current sexual health concerns and any sexual trauma. This information can help members of your healthcare team give you the best care. Some sexual activities may call for different types of care to keep you safe and comfortable. You should never be shamed or denied medical care because of your sexual history, gender or orientation. You deserve to receive care from healthcare professionals who will respect and address all your medical needs. If you are not comfortable with a healthcare professional, find another one who will support you. Try asking a healthcare professional you do trust for a referral.

If you are part of the lesbian, gay, bisexual, transgender, queer, intersex or asexual (LGBTQIA+) community, you can find healthcare providers who understand your needs by visiting the LGBTQ+ Healthcare Directory at www.lgbtqhealthcaredirectory.org or OutCare at www.outcarehealth.org to search their directories.

Finding Sexual Health Professionals. To find a sex therapist, visit www.aasect.org/find-professional to use the American Association of Sexuality Educators, Counselors and Therapists' Referral Directory. You can view each professional's areas of specialization, such as LGBTQIA+, illness, marriage counseling or trauma.

Other organizations where you can find healthcare professionals trained in sexual health include:

- Sexual Medicine Society of North America: www.smsna.org
- International Society for the Study of Women's Sexual Health: www.isswsh.org
- Scientific Network on Female Sexual Health and Cancer: www.cancersexnetwork.org
- The North American Menopause Society: www.menopause.org

See *Other Helpful Resources* on page 13 for additional contact information and for other helpful organizations.

Managing Sexual Side Effects

An important part of managing side effects that impact your sexual health is to determine what factors may be causing or contributing to the changes you are experiencing, so that you can address them.

Lack of Desire. During cancer treatment, many things can contribute to a lack of desire including, but not limited to:

- Anxiety or worry
- Depression
- Fatigue
- Pain or discomfort
- Nausea and/or vomiting
- Body image concerns—changes to physical appearance, such as weight gain or loss, hair loss, or the presence of a central line or port
- Hormonal changes, including early menopause (See *Early Induced or Premature Menopause* on page 5.)
- Some medications

If hormonal changes are contributing to lack of desire, hormone therapy may help:

- **Estrogen Therapy**—Some chemotherapy drugs and radiation to the pelvis can cause the ovaries to produce less estrogen. Estrogen therapies come in the form of pills, creams, patches and vaginal rings. However, if you have a history of hormone-driven breast, ovarian, or endometrial (uterine) cancer, estrogen therapy may not be safe for you. Speak to your healthcare team about possible treatment options for you.
- **Testosterone Therapy**—Some chemotherapy drugs and radiation to the pelvis, specifically the testicles, can cause a decrease in testosterone production. If a low testosterone level is causing your lack of desire, you may benefit from testosterone therapy. Testosterone therapies come in the form of injections, pills, patches and gels. However, if you have a history of prostate cancer, testosterone therapy may not be safe for you. Speak to your healthcare team about possible treatment options for you.

Non-hormonal therapies may be helpful for decreased sexual desire. For example:

- **Flibanserin (Addyi®)**—This non-hormonal medication is approved by the United States Food and Drug Administration (FDA) for the treatment of premenopausal individuals with hypoactive sexual desire disorder. It can take 8 to 12 weeks to achieve the maximum benefits from this drug, but side effects are minimal. Talk with your healthcare team to see if flibanserin might be a treatment option for you.

Talk to your healthcare team about your options to address the physiological impact cancer treatment(s) have on your desire and sexual function.

Several things can contribute to a lack of desire, but there are ways to help. Considerations include:

- Anxiety, worry and/or symptoms of depression—These can all cause lack of desire. Ask for a referral to a mental health professional. You may benefit from talk therapy and/or medications.

Visit www.LLS.org/booklets to view *Managing Stress: How stress affects you and ways to cope*.

- If you are taking antidepressants or pain medication, ask about adjusting your dosage or exploring a different medication. Both antidepressants and pain medications can either cause or contribute to lack of desire and may impact other aspects of sexual function.
- Address any other physical side effects, such as pain, nausea and/or vomiting, or fatigue, that may be contributing to your lack of desire. Discuss ways to manage these side effects with members of your treatment team. Ask for a referral to palliative (supportive) care.
 - If needed, take medication for pain or nausea and/or vomiting 30 to 60 minutes before sexual or intimate activity.

Visit www.LLS.org/booklets (filter by Side Effect Management) to view the full side effect management series.

Erectile Disorder. Erectile disorder, also called “erectile dysfunction (ED),” can include difficulty achieving or maintaining an erection or erections that are less firm. This can make vaginal, oral or anal sex difficult and less enjoyable. The cause of ED can be either psychological and/or physical. Your healthcare team can help you determine the cause. If the cause is physical, you have several options. They include:

- Prescription medications—Phosphodiesterase-5 (PDE5) inhibitors help the blood vessels relax and increase blood flow to the penis. Common medications include:
 - **Sildenafil (Viagra®)**
 - **Tadalafil (Cialis®)**
 - **Vardenafil (Levitra®, Staxyn®)**
 - **Avanafil (Stendra®)**
- Penile injections—Shots given into the penis, before sex, to help cause and sustain an erection. **Trimix**, a compound of **papaverine**, **phentolamine** and **alprostadil**, is commonly used. Other combinations or a single-ingredient injection may also be prescribed.

- A vacuum constriction device (or pump)—A plastic tube placed over the penis. Air is then pumped out of the device, creating suction. This suction causes more blood to flow to the penis.
- A combination of these medications/treatments may also help.

Note: Over-the-counter products and supplements claiming to help with ED or improve sexual performance may not be safe or effective. Talk to your healthcare team before trying any of these products.

Anxiety and symptoms of depression can also cause changes in erection. Ask for a referral to a mental health professional. You may benefit from talk therapy and/or a combination of therapy and medications.

Lubricants are not treatments for ED but using lubricants during sex can make sexual intercourse more comfortable for both partners. Water-based and silicone-based lubricants are safe to use with condoms and dental dams. Silicone-based lubricants are a good option for anal sex, as they dry out less quickly than water-based lubricants. Oil-based lubricants are also an option; however, they can break down latex condoms and dental dams, making them less effective.

Vaginal Dryness. Some chemotherapy drugs and radiation to the pelvis can cause vaginal dryness and pain. Vaginal dryness is often related to a decrease in estrogen levels causing early menopause or exacerbating menopausal signs and/or symptoms. See *Early Induced or Premature Menopause* in the right column. Options to improve vaginal dryness include:

- Using a lubricant during sex
 - Use water-based and silicone-based lubricants with condoms and dental dams. Other lubricants, such as oil-based lubricants, can break down latex, making condoms and dental dams less effective.
 - Avoid scented, flavored and/or warming lubricants. These can irritate the vulva and vagina, making dryness worse or increasing discomfort.
 - Choose paraben and glycerin-free products to help avoid irritation.
 - If you do not need to use a condom or dental dam to protect against pregnancy and/or sexually transmitted infections, common organic oils, such as coconut oil and olive oil, may be used as lubricants.
- Vaginal moisturizers
 - Vaginal moisturizers are different from lubricants. Moisturizers are not typically used for intercourse.

Rather, if used regularly, they improve overall dryness and vaginal health and make intercourse more comfortable.

- Localized, low-dose estrogen products
 - A low-dose estrogen cream or tablet applied directly to the area or a low-dose vaginal ring that releases estrogen can help with vulvar or vaginal dryness or pain. Talk to your healthcare team about the risks and benefits of localized estrogen therapy.

Arousal and/or Orgasm Difficulty. Chemotherapy or radiation to the pelvis can also decrease the functionality of blood vessels and nerves in the pelvis leading to difficulty with becoming aroused and reaching orgasm. Options to improve arousal/orgasm include:

- Vibration therapy
 - Vibrators help to increase blood flow to the genitals and nerve sensitivity. There are external, internal or combination vibrators available.
- An Eros device
 - The Eros clitoral therapy device is a medical device approved by the FDA. It is a small, hand-held device that sits over the glans clitoris to increase blood flow to the tissues through a gentle vacuum leading to greater genital sensitivity. Talk to members of your healthcare team to see if this option might work for you.

Early Induced or Premature Menopause. Menopause, the end of menstruation, is caused by a natural decline in reproductive hormones, and typically occurs in people who are between 45 and 55 years of age. Some chemotherapy drugs and radiation to the pelvis can cause the ovaries to produce less estrogen. The decrease in estrogen levels can cause interruptions or changes to the menstrual cycle, including early menopause. Even if the menstrual cycle does not change, estrogen levels may be lower than before treatment. For some patients, their menstrual cycle may return after treatment ends. Symptoms of menopause and/or low estrogen levels can include decreased sexual desire and vaginal dryness.

Menopause does not mean the end of sexual desire, pleasure and intimacy. Many people continue to have fulfilling sex lives after menopause.

Estrogen therapies can help address the symptoms of menopause including:

- Vaginal dryness (see *Vaginal Dryness* in the left column)
- Lack of desire (see *Lack of Desire* on page 4.)

- Hot flashes
- Sleep problems
- Mood changes

Ask your doctor about hormone therapies that will increase estrogen production and if they are safe for you to use. Estrogen therapies (alone or in combination with progesterone) come in pills, creams, patches and vaginal rings. If you have a history of hormone-driven breast, ovarian or endometrial (uterine) cancer, estrogen therapies may not be safe for you.

In addition to systemic estrogen therapies, there are other ways to manage the symptoms of menopause. Discuss ways to manage them with members of your healthcare team. For example, lubricants, vaginal moisturizers and/or localized, low-dose estrogen products can help with vaginal dryness. Changing your bedtime routine may help with sleep problems. Working with your healthcare team, find strategies that work for you.

Protecting Yourself and Your Partner

Consent. “Consent” is an agreement to engage in sexual activity. Open and ongoing communication is an important part of safe and enjoyable sexual experiences. Tell your partner what you enjoy and what your boundaries are. Respect your partner’s boundaries. If having sex (or a sexual activity) makes you feel uncomfortable, tell your partner and ask them to stop. The choice to have sex or engage in sexual play is always yours. Even if you were sexually active before your cancer diagnosis, only continue or resume having sex if you are physically and emotionally ready.

Consent to one sexual activity is not consent to all sexual activities. Consent to sexual activities in the past is not consent in the present. Consent can be withdrawn at any time, even during sexual activity. Physical response, such as vaginal lubrication or penile erection, is not consent. Consent cannot be given under fear or intimidation. Consent cannot be given by someone who is under age, under the influence of drugs or alcohol, asleep or unconscious.

If you have experienced sexual assault, call the National Sexual Assault Hotline at (800) 656-HOPE (4673).

Preventing Pregnancy. Getting pregnant during cancer treatment can be unsafe for both the pregnant person and the fetus. For some treatments, doctors may advise patients to use birth control for up to 1 year after treatment ends. Treatment may cause changes to the menstrual cycle, including early menopause. (See page 5.) Even if

the menstrual cycle stops during treatment, you may still be able to become pregnant, so it is best to continue to use birth control. Birth control methods include:

- **Abstinence**—Abstinence is really the only 100 percent effective way of preventing pregnancy. Abstinence does not mean the lack of sexual intimacy. There are many ways to be sexually connected and satisfied without engaging in vaginal penetration.
- **Condoms**—Both condoms worn over the penis and condoms inserted into the vagina prevent pregnancy by stopping sperm from entering the vagina. Condoms can be used with other forms of birth control to increase effectiveness. Condoms also offer protection against sexually transmitted infections (STIs). Condoms that cover the penis offer the most protection. Other forms of birth control do **not** offer protection against STIs.
- **Oral birth control**—These are pills that release hormones (progestin-only or a combination of hormones) to stop the ovaries from releasing an egg and thicken cervical mucus to help stop sperm from entering the uterus. A common example of oral birth control is a pack of 28 pills. You take one pill at the same time every day. The first 21 pills (3 weeks) are active pills that contain hormones. The remaining seven pills (1 week) are inactive (placebo) pills. (Not every pack includes inactive pills. If yours does, you do not have to take them; however, doing so reinforces the habit of taking a daily pill.) When you are not taking the active pills, you may experience a bleed similar to a menstrual period. When you finish a pack, you will start a new one. This is just one example of an oral birth control regime. Ask your prescribing healthcare professional for specific instructions. There are multiple options for oral birth control making it easy to find one that fits your needs. Do not be afraid to ask to switch to another option if one is not working for you.
- **Intrauterine device (IUD)**—This is a small T-shaped device that is placed in the uterus by a healthcare professional. Hormonal and non-hormonal options are available. Depending on the device used, an IUD can last anywhere from 3 to 10 years.
- **Implant**—This is a small device placed under the skin in the upper arm by a healthcare professional. Implants are effective for 3 years. The implant releases progestin.
- **Shot**—This injection of progestin is given by a healthcare professional. It is effective for 3 months.

- **Vaginal ring**—This is a flexible ring that releases hormones. It is inserted into the vagina. Depending on the type of ring, the ring stays in place for 3 to 5 weeks. It is then removed to allow for a bleed similar to a menstrual period and/or to be replaced.
- **Patch**—A patch, similar to a sticker, that releases hormones, is placed on the skin weekly.
- **Spermicide, either with or without a diaphragm or cervical cap**—Spermicides are creams, gels, foams, suppositories or films that are placed in the vagina before sex to prevent sperm from reaching an egg. To better prevent pregnancy, spermicide can be combined with the use of a diaphragm or cervical cap (soft silicone cups placed in the vagina to cover the cervix). Spermicide may increase the risk of urinary tract infections (UTIs). Other forms of birth control may be more appropriate during cancer treatment.
- **Non-hormonal vaginal bioadhesive gel—lactic acid, citric acid and potassium bitartrate (Phexxi®)** is an FDA-approved non-hormonal on-demand method of birth control used to prevent pregnancy. The gel is placed in the vagina before sexual intercourse. The gel works immediately and lasts up to 1 hour. It can be used with condoms or a diaphragm for additional protection. Do not use it with a vaginal ring. According to the manufacturer, in rare cases, bladder and kidney infections have been reported; therefore, people with a history of UTIs should not use the gel.

Emergency contraception pill (also known as the “morning-after pill”)—This pill, that can be taken after unprotected sex, releases hormones to prevent ovulation and thicken cervical mucus to prevent pregnancy. The sooner the pill is taken after unprotected sex, the more effective it is. Emergency contraception pills made with **levonorgestrel (Plan B One-Step®)** are available over the counter without a prescription. They can be effective up to 72 hours (3 days) after unprotected sex. A different emergency contraception pill, **ulipristal acetate (Ella®)**, is available with a prescription and can be effective up to 120 hours (5 days) after unprotected sex. **The morning-after pill is not meant to be used as a regular form of birth control.**

Note: Some studies suggest that pills made with levonorgestrel may be less effective for people who weigh more than 165lb or have a body mass index (BMI) over 25. The FDA says data on weight and effectiveness of levonorgestrel emergency contraceptives (LNG ECs) are “conflicting and too limited to make a definitive conclusion.” The FDA reports, “There are no safety

concerns that preclude use of LNG ECs in women generally, and the FDA continues to believe all women, regardless of how much they weigh, can use these products to prevent unintended pregnancy following unprotected sexual intercourse or contraceptive failure.” According to the manufacturer’s website, ulipristal acetate (Ella®) may be less effective for people with a BMI over 30. Talk to your doctor if you have any concerns.

Some IUDs can be used as emergency contraceptive if put in up to 5 days after unprotected sex.

Birth Control and Effectiveness. Intrauterine devices and implants are the most effective forms of birth control. Other hormonal birth control methods (pills, the shot, the ring and the patch) are also very effective. Effectiveness decreases if these are not used correctly (for example, forgetting to take a birth control pill or replace a vaginal ring at the correct time).

Condoms can be combined with other forms of birth control to increase effectiveness. Condoms also protect against sexually transmitted infections (STIs).

Spermicide when used alone is less effective than condoms, hormonal birth control and non-hormonal IUDs at preventing pregnancy. Using spermicide along with a diaphragm or cervical cap increases effectiveness.

Other methods of birth control such as the pull-out method (removing the penis from the vagina before ejaculation) and fertility awareness (tracking the menstrual cycle to avoid sexual activity on fertile days) are much less effective at preventing pregnancy, especially when used alone. Due to the risks of pregnancy during cancer treatment, these methods are usually not recommended.

Talk to your doctor about what form(s) of birth control are best for you. **Get instructions for using your method of birth control. Follow the instructions exactly.**

Pregnancy and Chronic Blood Cancers. If you have a chronic blood cancer, such as chronic myeloid leukemia (CML), and you wish to become pregnant, speak to members of your healthcare team. With proper planning, a safe pregnancy while managing a chronic blood cancer may be possible. Members of your healthcare team may suggest waiting to conceive until your disease is well managed. You may also need to suspend or change treatment while trying to conceive and during pregnancy. Pregnant patients will require close observation from a hematologist-oncologist and an obstetrician who specializes in high-risk pregnancies.

Considerations for People Taking Testosterone. If you take testosterone, know that it is not a form of birth control. Although it does suppress ovulation, it does not always do so consistently, and you may still be able to become pregnant. Condoms, a copper IUD or hormonal birth control with progestin only may be good options if birth control is needed.

Preventing Sexually Transmitted Infections. Sexually transmitted infections (STIs), also called “sexually transmitted diseases (STDs),” are infections that can be spread through sexual contact, including oral, anal, or vaginal sex and genital touching. Sexually transmitted infections include:

- Chlamydia
- Gonorrhea
- Trichomoniasis
- Syphilis
- Pubic lice (crabs)
- Hepatitis B
- Herpes
- Human papillomavirus (HPV)
- Human immunodeficiency virus (HIV)/acquired immunodeficiency syndrome (AIDS)

Prevention. Condoms or other barrier protection, such as dental dams, during vaginal, anal or oral sex help to protect you and your partner from STIs. See *More About STIs, Treatment and Prevention* below to learn more about specific STIs, including signs and symptoms, treatments and more ways to protect yourself.

Testing for STIs. Talk to your healthcare team about what type of STI testing is recommended for you. Some STIs may not show any signs and/or symptoms in some people, but these infections can still be passed to others. Ask your partner to be tested, too. The type and frequency of STI testing depends on your sexual history and other factors. Visit

<https://www.cdc.gov/std/prevention/screeningrecs.htm>

to see the Centers for Disease Control and Prevention (CDC)’s screening recommendations.

More About STIs, Treatment and Prevention. Some STIs can be cured with treatment. Others can be managed with treatment. Early diagnosis and treatment of many STIs is important to decrease the risk of more serious medical issues developing and to prevent spreading the disease to others. If your white blood cell counts are low, you may be more at risk for infection, including STIs.

- Bacterial STIs (chlamydia, gonorrhea, trichomoniasis and syphilis) can usually be treated and cured with antibiotics. Common signs and/or symptoms of these infections include painful urination, vaginal or penile discharge, pain, itching and/or odor in the affected area. There may only be very mild signs and/or symptoms of syphilis at the time of infection; however, if it is left untreated, syphilis can spread and cause serious damage to internal organs.
- Pubic lice (similar to head lice) can be treated with over-the-counter medication.
- Hepatitis B clears on its own in 4 to 8 weeks in most adults; however, for some adults, hepatitis B can become a chronic (long-lasting) condition and lead to serious liver problems.
- Herpes is a viral infection that causes recurrent sores on the genitals and/or mouth. It is caused by two similar viruses: herpes simplex virus type 1 (HSV-1) and herpes simplex virus type 2 (HSV-2). While usually HSV-1 causes oral sores and HSV-2 causes genital sores, either type can infect either area if exposure occurs. There is no cure for a herpes infection, but the signs and symptoms can be managed with medication. Although these can be uncomfortable or even painful, a herpes infection does not usually cause any serious health issues in adults. Some people who have the herpes virus in their system show no signs or symptoms.
- Human papillomavirus (HPV) infection is very common. It is often harmless and goes away on its own; however, some types of HPV can lead to cancer, such as cervical cancer or penile cancer, or genital warts.
 - o The HPV vaccine offers protection against many of the types of HPV that can cause cancer and genital warts. The HPV vaccine is most effective if given before a person becomes sexually active. The CDC recommends the vaccine for children at 11 or 12 of age and up to 26 of age (if not vaccinated when younger). The vaccine may also be appropriate for some adults up to age 45.
- Human immunodeficiency virus (HIV) attacks the body’s immune system. If HIV is not treated, it can lead to acquired immunodeficiency syndrome (AIDS). Within 2 to 3 weeks after infection, some people experience flu-like symptoms (fever, chills, muscle aches and fatigue). Others may not experience symptoms. There is no cure for HIV or AIDS. With appropriate treatment, HIV can be controlled, and people with HIV can live long, healthy lives. HIV treatment reduces the amount of HIV in blood (the viral load). If a person with HIV reaches

and maintains an undetectable viral load, there is no risk that they will transmit HIV to an HIV-negative partner through sex.

If you are HIV-negative but at risk for HIV infection, medication regimens can greatly reduce your risk.

- o Pre-exposure prophylaxis (PrEP)—Medication or injections taken to prevent getting HIV. Pre-exposure prophylaxis may be appropriate for you if you have a partner with HIV, do not consistently use condoms, and/or have been diagnosed with an STI in the past 6 months.
- o Post-exposure prophylaxis (PEP)—Medication taken within 72 hours of possible exposure to HIV. Post-exposure prophylaxis should only be used in emergency situations. Pre-exposure prophylaxis (PrEP) can be used for long-term protection.
- A urinary tract infection, although not an STI, can be caused by bacteria introduced to the urinary tract during sexual activity. Urinary tract infections are more common in people assigned female at birth because the length of the urinary tract is shorter, making it easier for bacteria to enter the bladder. To help prevent UTIs:
 - o Drink plenty of water every day.
 - o Urinate after sex.
 - o Gently clean external genitals with warm water and mild, unscented soap.
 - o Avoid using harsh soaps, sprays, or douches. It is not necessary to use them in the genital area, and they can irritate the urethra.

Signs and/or symptoms of a UTI include pain when urinating, persistent urge to urinate and cloudy urine. Urinary tract infections can be cured with antibiotics. If left untreated, infection can spread to the kidneys, causing damage and decreasing kidney function. Research also shows that lack of hormones in the urogenital tract of people assigned female at birth (seen in induced or premature menopause) can increase the risk of UTIs.

Sexual Enhancement Aids. If you use sexual enhancement aids (commonly referred to as “sex toys”) such as vibrators, personal massagers, dildos, or other items, clean them well after every use to avoid infection. If your white blood cell counts are low, you may be more at risk for infection. If you are the only person using the toy, cleaning it with antibacterial soap and water and allowing it to air dry is usually sufficient. In the following cases, toys should be disinfected:

- Before being used on a different body part (mouth, vagina, anus)
- Before and after being used by another person
- If the toy has been used during a yeast or bacterial infection

Check your device’s manual for specific cleaning instructions. Depending on the material, toys may be disinfected in the dishwasher, by being boiled, or soaked in a 10 percent bleach/water solution. If the toy is mechanized (such as a vibrator), check the manual to see if the toy is water-safe. Many toys are splashproof, meaning they can be rinsed with water. Some toys are waterproof, meaning they can be submerged in water. Remove batteries prior to cleaning. Penetrative sex toys can be covered with a new condom before each use. Do not use silicone-based lubricants with silicone sex toys, as the lubricant can damage the toy. Store sex toys in a clean pouch or box between uses.

Other Considerations. Chemotherapy and other drugs can be present in bodily fluids such as saliva, semen and vaginal fluids for up to 48-72 hours depending on the drug. The risk of exposure to chemotherapy or other drugs during sexual activity are not clear. Ask your treatment team if you should take any precautions or avoid sexual activities for some time after treatment to protect your partner from exposure.

If you are receiving external beam radiation therapy, you will not expose your partner to radiation.

Sexual Self-care

Masturbation is the act of giving yourself sexual pleasure. It is a natural and healthy way to learn about your body and what feels sexually satisfying for you. If you masturbated before cancer treatment, you may notice changes to your desire to masturbate, ability to achieve an erection, vaginal dryness or ability to orgasm.

If cancer treatment has led to changes in your sexual health, masturbation may help you find new ways to feel sexual pleasure and become more comfortable with the changes to your body that cancer treatment can cause.

Some people choose to use personal massagers, vibrators, or other sex toys. Some vibrators can be purchased at pharmacies or specialty stores. Others can be ordered discreetly online. Clean and care for your toys properly to prevent infection. See *Sexual Enhancement Aids* in the left column.

You can talk to a sex therapist about masturbation. You do not have to be either in a relationship or dating to talk to a sex therapist.

Masturbation may not be a practice that you are comfortable with, for a variety of reasons. Speaking to a therapist can help you identify other ways for sexual self-care.

Communicating with Your Partner

Discussing experiences, feelings and concerns with your partner(s)—giving each other the chance to talk and listen—is an important part of maintaining or improving your quality of life and your intimate relationships.

Your partner may have their own concerns, such as being afraid of hurting you during sex, feeling guilty or selfish for wanting to be physically intimate with you, or not knowing how to talk about their feelings. Begin a discussion with a fact, belief, feeling and then follow up with an action. For example:

Ever since my cancer diagnosis you have stopped kissing me (fact), I believe it's because you aren't desiring me (belief), and it makes me sad that cancer has impacted this important part of our relationship (feeling). I would really love it if when you come home from work every day, you come and kiss me like you used to (action).

The key to communicating with your partner begins with a discussion. Both of you are under a lot of stress, so try to pick a good time to share your feelings. Your partner's own feelings will color their response. Some people's response will be careful. Others react immediately to what they think they heard (perhaps thinking or saying something like "You're only doing that because I asked you to.") Recognize that your partner's response lets you know how they felt about what you said. Acknowledge your partner's input and thank them for it. You will both feel valued and better understood responding openly and thoughtfully to each other.

You may not be interested in sex. Until your treatment is completed, and you feel better, you and your partner may need to find new ways to be intimate. For ideas on non-sexual ways to work on your relationship, see *Intimacy* in the right column.

If you do wish to continue having sex, ask your treatment team if it is safe to do so. Talk to your treatment team about any side effects or changes. See *Managing Side Effects* on page 3.

Ways to Prepare for Sex

- Take a warm shower or bath to help relax your body. You can invite your partner to join you, if you like.
- Take a nap before sex to help you feel less tired.
- If needed, take nausea or pain medication 30 minutes before sex.
- Set the mood. For example, light candles and play music.
- Use lubricants for comfort.
 - Water-based and silicone-based lubricants are safe to use with condoms and dental dams. Silicone-based lubricants are good option for anal sex, as they dry out less quickly than water-based lubricants. Oil-based lubricants are also an option; however, they can make latex condoms and dental dams less effective.
- Start slowly with other forms of physical touch such as kissing, massaging, or touching.
- Remember that climax or orgasm is not required for sex to be enjoyable. Try not to put pressure on yourself or your partner. Seek to enjoy the moment.
- Tell your partner what feels good to you.
- If you and your partner are both comfortable with your sexual activity, you can try using sexual enhancement aids.

You can also ask for a referral to a sex therapist. A sex therapist can help you address any difficulties you may encounter and improve communication between you and your partner. To find a sex therapist, visit www.aasect.org/find-professional to use the American Association of Sexuality Educators, Counselors and Therapists' Referral Directory. (See *Finding Sexual Health Professionals* on page 3.)

Intimacy. Intimacy is closeness between people in personal relationships. Sex and intimacy are not mutually exclusive; one can exist without the other. In some relationships, sex can build intimacy and/or emotional intimacy may lead to physical intimacy and sex. However, an intimate relationship does not have to include sex. Sex is not the only way to build or maintain intimate relationships. Additionally, physical intimacy is not always sexual. For example, hugging a friend is a form of intimacy. Trust, safety, communication and acceptance are the most important aspects of intimate relationships.

Ways to Build Intimacy Without Sex

- 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 them.

Sexual Health and Intimacy

- Set aside time to be alone together. Take your time. Appreciate and enjoy each other and the gift of being able to be fully open with one another.
- Lie naked together.
- Enjoy a meal together.
- Talk a walk together.
- Read a book or watch a movie together and discuss it afterwards.
- Try a new activity together, such as a painting class.
- If you are comfortable, explore other types of physical intimacy; touching, kissing, cuddling, holding hands or massage.
- Ask your healthcare team for a referral to a therapist for couple's counseling to help improve communication.

Dating

If you are dating or interested in dating, a cancer diagnosis does not mean you have to stop as long as you feel up for it. Remember, every date before your diagnosis probably did not go perfectly. You may have bad dates after your diagnosis as well. You may also meet incredible, new people. You may find it helpful to take some time to reflect on your goals for dating and what you want in a partner. Some people find that a cancer diagnosis changes their priorities.

You may be wondering how to tell someone about your cancer diagnosis. One way to get comfortable telling your story is role playing with a friend. For example, you could act as though you were on a date and wanted to disclose your cancer diagnosis. Other approaches that may also help include:

- Sharing your story at a time that is comfortable for you—there is no right or wrong time, either to tell or not to tell. However, it is probably better that disclosure happens before a close emotional attachment develops. If you find out that the other person is uncomfortable about you either having cancer or being a survivor, you will be aware that there is a possibility of heartache and/or conflict.
- Taking 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.
- Telling your friends about your worries or fears so you have people to encourage you.
- Telling your friends about any negative thoughts you have and ask them to challenge these thoughts or give you a reality check.
- Talking to a social worker or therapist about your concerns.
- Turning to the people in your life who are supportive and will help you maintain a positive self-view. Nurture these relationships.

Acknowledgement

The Leukemia & Lymphoma Society appreciates the review of this material by:

Sage Bolte, PhD, LCSW, CST

Chief Philanthropy Officer and President
Inova Health Foundation
Falls Church, VA

Aleece Fosnight, MSPAS, PA-C, CSCS, CSE, NCMP, IF

Founder, Owner, CEO, Fosnight Center for Sexual Health
Sexual Medicine, Women's Health, Urology
Asheville, NC
Adjunct Faculty, Brevard College
Brevard, NC
American Association of Sexuality Educators, Counselors
and Therapists (AASECT) Certified Sexuality Counselor/
Supervisor
AASECT Certified Sexuality Educator

Resources and Information

LLS is the world's largest voluntary health organization dedicated to funding blood cancer research, education and patient services. LLS has regions throughout the United States and in Canada. To find the region nearest to you, visit our website at www.LLS.org/LocalPrograms or contact an Information Specialist at (800) 955-4572.

LLS offers free information and services for patients and families affected by blood cancers. This section lists various resources you may find helpful.

For Help and Information

Consult with an Information Specialist. Information Specialists can assist you through cancer treatment, financial and social challenges and give accurate, up-to-date disease, treatment and support information. Our Information Specialists are highly trained oncology social workers and nurses. Language services are available. For more information, please:

- Call: (800) 955-4572 (Monday through Friday, 9 a.m. to 9 p.m. ET)
- Email and Live chat: www.LLS.org/InformationSpecialists

Clinical Trials (Research Studies). Research is ongoing to develop new treatment options for patients. LLS offers help for patients and caregivers in understanding, identifying and accessing clinical trials. Pediatric and adult patients and caregivers can work with our Clinical Trial Nurse Navigators who will help find clinical trials and provide personalized support throughout the entire clinical trial process. Visit www.LLS.org/CTSC for more information.

Nutrition Consultations. Schedule a free one-on-one nutrition consultation with one of our registered dietitians who have expertise in oncology nutrition. Consultations are available to patients and caregivers of all cancer types. Dietitians can assist with information about healthy eating strategies, side effect management and more. Please visit www.LLS.org/nutrition for more information.

Free Information Booklets. LLS offers free education and support booklets for patients, caregivers and healthcare professionals that can either be read online or ordered. Please visit www.LLS.org/booklets for more information.

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

Financial Assistance. LLS offers financial support to eligible individuals with blood cancer for insurance premiums, co-pays, and non-medical expenses like travel, food, utilities, housing, etc. For more information, please:

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

Podcast. *The Bloodline with LLS* is here to remind you that after a diagnosis comes hope. Listen in as patients, caregivers, advocates, doctors and other healthcare professionals discuss diagnosis, treatment options, quality-of-life concerns, treatment side effects, doctor-patient communication and other important survivorship topics. Visit www.LLS.org/TheBloodline for more information and to subscribe to access exclusive content, submit ideas and topics, and connect with other listeners.

Free Mobile Apps.

- LLS Coloring For Kids™ – Allows children (and adults) to express their creativity and offers activities to help them learn about blood cancer and its treatment. Visit www.LLS.org/ColoringApp to download for free.
- LLS Health Manager™ – Helps you track side effects, medication, food and hydration, questions for your doctor, and more. Visit www.LLS.org/HealthManager to download for free.

Suggested Reading. LLS provides a list of selected books recommended for patients, caregivers, children and teens. Visit www.LLS.org/SuggestedReading to find out more.

Connecting with Patients, Caregivers and Community Resources

LLS Community. The one-stop virtual meeting place for talking with other patients and receiving the latest blood cancer resources and information. Share your experiences with other patients and caregivers and get personalized support from trained LLS staff. Visit www.LLS.org/community to join.

Weekly Online Chats. Moderated online chats can provide support and help cancer patients and caregivers reach out and share information. Please visit www.LLS.org/chat for more information.

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

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

Advocacy and Public Policy. Working closely with dedicated volunteer advocates, LLS's Office of Public Policy elevates the voices of patients to state and federal elected officials, the White House, governors and even courts. Together, we advocate for safe and effective treatments. We pursue policies that would make care more accessible to all patients. And, most of all, we advocate for the hope for a cure. Want to join our work? Visit www.LLS.org/advocacy for more information.

Other Helpful Organizations. LLS offers an extensive list of resources for patients and families. There are resources that provide help with financial assistance, counseling, transportation, patient care and other needs. For more information, please visit www.LLS.org/ResourceDirectory to view the directory.

Additional Help for Specific Populations

Información en Español (LLS information in Spanish). Please visit www.LLS.org/espanol for more information.

Language Services. Let members of your healthcare team know if you need translation or interpreting services because English is not your native language, or if you need other assistance, such as a sign language interpreter. Often these services are free.

Sexual Health and Intimacy

Information for Veterans. Veterans who were exposed to Agent Orange while serving in Vietnam may be able to get help from the United States Department of Veterans Affairs. For more information, please

- Call: the VA (800) 749-8387
- Visit: www.publichealth.va.gov/exposures/AgentOrange

Information for Firefighters. Firefighters are at an increased risk of developing cancer. There are steps that firefighters can take to reduce the risk. Please visit www.LLS.org/FireFighters for resources and information.

World Trade Center Health Program. People involved in the aftermath of the 9/11 attacks and subsequently diagnosed with a blood cancer may be able to get help from the World Trade Center (WTC) Health Program. People eligible for help include:

- Responders
- Workers and volunteers who helped with rescue, recovery and cleanup at the WTC-related sites in New York City (NYC)
- Survivors who were in the NYC disaster area and those who lived, worked or were in school in that area
- Responders to the Pentagon and the Shanksville, PA, crashes

For more information, please

- Call: WTC Health Program at (888) 982-4748
- Visit: www.cdc.gov/wtc/faq.html

People Suffering from Depression. Treating depression has benefits for cancer patients. Seek medical advice if your mood does not improve over time, for example, if you feel depressed every day for a two-week period. For more information, please:

- Call: The National Institute of Mental Health (NIMH) at (866) 615-6464
- Visit: NIMH at www.nimh.nih.gov and enter “depression” in the search box

Other Helpful Resources

Academy of Pelvic Health and Physical Therapy
(844) 576-4055
www.aptapelvichealth.org

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

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.

The American Society for Reproductive Medicine

(205) 978-5000

www.asrm.org

Provides information on reproductive medicine, including infertility, menopause and sexuality. Patient and professional websites are available.

Association of Oncology Social Work

(847) 686-2233

<https://aosw.org/patients-caregivers/find-an-osw-near-me>

The Association of Oncology Social Work (AOSW) is an international nonprofit organization dedicated to the enhancement of psychosocial services to people with cancer and their families.

CancerCare®

(800) 813-4673

www.cancercares.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.

International Society for the Study of Women's Sexual Health

(952) 683-9025

www.isswsh.org

Provides the public with accurate information about women's sexuality and health.

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.

National LGBT Cancer Network

(212) 675-2633

<https://cancer-network.org>

Seeks to improve the lives of LGBT cancer survivors and those at risk.

The North American Menopause Society

(440) 442-7550

www.menopause.org/for-women

Provides information and resources on menopause and women's health.

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.

Scientific Network on Female Sexual Health and Cancer

(952) 683-9044

www.cancersexnetwork.org

The Scientific Network on Female Sexual Health and Cancer is a global interdisciplinary network of clinicians, researchers and healthcare professionals who work to promote sexual well-being in women and girls affected by cancer by advancing evidence-based education and practice.

Sexual Medicine Society of North America

www.smsna.org/patients

Provides information on a broad range of sexual health conditions and a directory of healthcare providers.

Stupid Cancer

(212) 619-1040

www.stupidcancer.org

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

References

American College of Obstetricians and Gynecologists. "Effectiveness of Birth Control Methods." October 2021. <https://www.acog.org/womens-health/infographics/effectiveness-of-birth-control-methods>. Accessed December 16, 2022.

Brown University. "What's the Best Way to Clean Sex Toys?" <https://www.brown.edu/campus-life/health/services/promotion/sexual-health-sex-101/sex-toys>. Accessed February 23, 2023.

Centers for Disease Control and Prevention (CDC). Pre-Exposure Prophylaxis (PrEP). Last reviewed July 5, 2022. <https://www.cdc.gov/hiv/risk/prep/index.html>. Accessed December 16, 2022.

Centers for Disease Control and Prevention (CDC). "Urinary Tract Infection." Last reviewed October 6, 2021. <https://www.cdc.gov/antibiotic-use/uti.html>. Accessed December 16, 2022.

Cleveland Clinic. Birth Control Options. April 12, 2019. <https://my.clevelandclinic.org/health/articles/11427-birth-control-options>. Last reviewed 8/18/2022. Accessed December 16, 2022.

Mayo Clinic. Cancer survivors: Late effects of cancer treatment. November 4, 2022. <https://www.mayoclinic.org/diseases-conditions/cancer/in-depth/cancer-survivor/art-20045524>. Accessed February 4, 2023.

Memorial Sloan Cancer Center. Penile Injection Therapy. Last updated May 21, 2021. <https://www.mskcc.org/cancer-care/patient-education/penile-injection-therapy>. Accessed December 16, 2022.

US Food & Drug Administration (FDA). Plan B (0.75mg levonorgestrel) and Plan B One-Step (1.5 mg levonorgestrel) Tablets Information. May 19, 2016. <https://www.fda.gov/drugs/postmarket-drug-safety-information-patients-and-providers/plan-b-075mg-levonorgestrel-and-plan-b-one-step-15-mg-levonorgestrel-tablets-information>. Accessed December 16, 2022.

This publication is designed to provide accurate and authoritative information about the subject matter covered. It is distributed as a public service by The Leukemia & Lymphoma Society (LLS), with the understanding that LLS is not engaged in rendering medical or other professional services. LLS carefully reviews content for accuracy and confirms that all diagnostic and therapeutic options are presented in a fair and balanced manner without particular bias to any one option.

LLS provides information on other organizations and resources as a courtesy and in no way implies endorsement of the organizations listed. LLS reserves the right to include/exclude any organization at its own discretion.



LEUKEMIA &
LYMPHOMA
SOCIETY®

Information Specialist: **800.955.4572**

The mission of The Leukemia & Lymphoma Society (LLS) is to cure leukemia, lymphoma, Hodgkin's disease and myeloma, and improve the quality of life of patients and their families. Find out more at www.LLS.org.