

Highlights

- The term “fertility” is used to describe the ability to conceive a child naturally. Some cancer treatments affect fertility in males and females.
- The risk of infertility from cancer treatment is based on several factors, including the patient’s age and the type and dosage of treatment received.
- It is important to talk with members of your oncology team before treatment begins about the effects of your treatment.
- There are options that may help you preserve the ability to have children in the future. Some options require action to be taken before treatment begins.
- Sperm cryopreservation (sperm banking) is cited by the American Society of Clinical Oncology (ASCO) as the fertility preservation method with the highest likelihood of success for male cancer survivors. Embryo freezing is the method with the highest likelihood of success for female cancer survivors.
- Most cancer survivors who can conceive after treatment have normal pregnancies and healthy babies. However, patients should talk to their oncologists about any potential risks they face regarding conception or pregnancy.
- Even if an individual is infertile, it does not mean he or she cannot contract a sexually transmitted disease, so it is necessary to practice safe sex. For more information about sexuality and intimacy, please visit www.LLS.org/sexuality.

Introduction

Chemotherapy and radiation can cause “late” effects that may manifest months or years after treatment has ended. One possible late effect is infertility, the inability to conceive a child naturally. When first diagnosed with leukemia or lymphoma, your primary concern will be your upcoming treatment and long-term survival. You may not be thinking about whether you can one day become a parent. However, information about the potential effects of your treatment can help you take steps to maximize your ability to have a child in the future.

This publication provides information about:

- How treatment for blood cancers can affect fertility.
- Steps you may be able to take before, during or after treatment to preserve your ability to have children in the future.
- Suggestions for talking with your oncology team about fertility.
- Resources for additional information and support.

This publication only provides general information. Speak with members of your healthcare team about the specific effects of your treatment and the options that are available to you.

You can read more about other late effects in the free LLS publications, *Long-Term and Late Effects of Treatment for Childhood Leukemia or Lymphoma Facts* and *Long-Term and Late Effects of Treatment in Adults Facts*.

Cancer and Fertility

Some patients have impaired fertility even before starting treatment. For example, about two out of every three male patients with Hodgkin lymphoma have a low sperm count at the time of diagnosis.

Not all cancer treatments affect fertility. Your risk depends on several factors, including

- Your age at the time of diagnosis
- The type and dosage of chemotherapy drug(s) you receive
 - Alkylating agents, for example cyclophosphamide or procarbazine, have the most significant effect on fertility. Other drugs are generally less toxic to sperm-forming cells and eggs, but can also cause infertility, especially when used as part of a combination of therapies.

- The location and dosage of radiation
 - Exposure to the testes may destroy cells that form sperm.
 - Exposure to the ovaries may destroy eggs.
 - Exposure to the pituitary gland in the brain may cause changes in secretion of hormones that regulate puberty and fertility.
- Whether you received a blood or marrow stem cell transplantation, which is associated with a high risk of infertility.

Possible effects on males

- Loss of sperm production can be temporary or permanent.
- If sperm production recovers, this can take one to five years.

Analysis of a semen sample can indicate if you are making sperm. This can be done one year or later after treatment is completed. Talk with your doctor about how often to be evaluated.

A note to parents: Some chemotherapies and radiation therapies can affect the endocrine system, the glands and cells that control growth and development. Talk with your son's doctor if your son seems to be going through puberty early (before age 9) or has not entered puberty by age 15. The doctor will want to evaluate him and may prescribe medicine to alleviate the hormone imbalance.

Possible effects on females

- Females do not produce new eggs. Therefore, the effect of treatment will depend on how many eggs remain after treatment.
- If all the eggs are destroyed, a woman will lose ovarian function immediately after treatment. Premature ovarian failure (POF), also called premature menopause, describes a loss of ovarian function in a woman younger than 40. Unlike menopause, this is not a natural occurrence. When POF is caused by cancer treatment, it is unlikely that a girl or woman will have subsequent menstrual periods or be able to become pregnant naturally again. Generally, POF is managed with hormone replacement therapy, including estrogen and progesterone. Girls and women with POF are encouraged to eat a healthy diet and exercise regularly (aerobics and weight training) to decrease the health risks of osteoporosis and heart disease. Calcium and vitamin D supplements for bone health may also be prescribed.
- If some eggs remain after treatment, a woman may still menstruate regularly and remain fertile after treatment, but she may develop POF and lose ovarian function at a young age. If you are at risk for POF, you may want to start a family early. If you are fertile after treatment but not ready to start a family, you may want to consider egg or embryo freezing (see page 3).

- Radiation to the pelvic area can cause damage to the uterus, increasing the risk for infertility, miscarriage, or premature birth.
- Females who undergo cancer treatment as children tend to have fewer fertility problems than females treated during the teen or adult years.
- Changes in your body or difficulty conceiving may or may not be related to the effects of your cancer treatment. Talk with your doctor if you have:
 - Irregular menstrual cycles
 - Hot flashes
 - Breast tenderness
 - Painful intercourse
 - Trouble getting pregnant
 - A history of miscarriages
 - Any other questions or concerns.

A note to parents: Some chemotherapies and radiation therapies can affect the endocrine system, the glands and cells that control growth and development. Talk with your daughter's doctor if she seems to be going through puberty early (before age 8) or has not entered puberty by age 15. The doctor will want to evaluate her and may prescribe medicine to alleviate the hormone imbalance.

Options to Preserve Fertility Before Treatment

Depending on how ill you are at the time of diagnosis, and how much time you have before you start treatment, you may be able to take steps before treatment begins to preserve your fertility potential.

Options for Males

- **Sperm banking (cryopreservation)**—This involves the collection of semen through masturbation. If there are sperm in the semen, it is frozen and stored for possible future use. This is the fertility preservation option with the highest likelihood of success for men.
- **Electroejaculation**—For males who are unable to ejaculate by masturbation because of, for example, religious beliefs, pain or embarrassment, semen can be collected under anesthesia. An electrical current is used to stimulate ejaculation.
- **Testicular sperm extraction (TESE)**—For males who have no sperm in the semen specimen, this surgical procedure performed under anesthesia can be considered. The doctor removes pieces of tissue from the testes, which are then examined for mature sperm. These can be removed from the tissue and frozen for possible future use.

- **Testicular tissue freezing**—Boys who have not yet gone through puberty do not produce mature sperm, so they cannot sperm bank. They may be able to undergo an experimental surgical procedure in which a doctor removes tissue from the testicle to be frozen for possible future use. This technique, however, has not yet resulted in a pregnancy. Further research is needed.
- **Radiation testicular shielding**—If the testes will be exposed to radiation, the doctor may be able to cover them with external shields. This must be planned before treatment begins, and the shields must be used each day of treatment. Not all patients will be able to use shields, as sometimes there is a need to treat the testes with radiation.

Options for Females

- **Embryo freezing**—This involves about 10 days of hormone injections to stimulate the ovaries followed by retrieval of mature eggs performed under anesthesia. The eggs are fertilized in the laboratory with sperm from a partner or donor to create embryos (IVF or in vitro fertilization). The embryos are then frozen and stored for possible future use. Embryo freezing is the option with the highest likelihood of success for females. The process typically takes at least two to three weeks.
- **Egg freezing**—This involves about 10 days of hormone injections to stimulate the ovaries, followed by retrieval of mature eggs performed under anesthesia. The eggs are then frozen and stored for possible future use without being fertilized. The process typically takes at least two to three weeks.
- **Ovarian tissue freezing**—Girls who have not yet gone through puberty have no mature eggs, and women who must start treatment quickly do not have the two to three weeks required to undergo egg or embryo freezing. They may be able to undergo a procedure in which part of the ovary (or the entire ovary) is removed and frozen for possible future use. Only a small number of pregnancies have resulted from re-implanting tissue, and this may not be safe for patients with certain types of cancer. Further research is needed.
- **Ovarian transposition**—If the ovaries will be in the radiation treatment field, patients may undergo this minor surgical procedure in which a doctor moves the ovaries outside of the radiation field to minimize exposure and radiation damage.
- **Gonadotropin-releasing hormones (GnRHs)**—This is a medication used during chemotherapy to suppress ovarian function and possibly protect the eggs from damage. Further research is needed.

Options For Having a Family After Treatment

Many men and women will be able to conceive naturally after cancer treatment. Patients are generally recommended to wait at least two years after treatment is completed before attempting conception. Check with your doctor to find out how long after treatment you should wait. If you are not able to conceive naturally, there are a number of other ways to build a family.

Options for Males

- **Use of your frozen sperm**—Depending on the number of vials you have stored and the number and quality of the specimens, this may be used for artificial insemination (the injection of semen into part of the female reproductive tract by a method other than sexual intercourse). For many men, your female partner can undergo an IVF cycle to remove mature eggs so they can be fertilized in the laboratory with your sperm. The embryos created are transferred to her uterus.
- **In Vitro Fertilization (IVF)**—If you have a low sperm count, your female partner can undergo an IVF cycle to remove mature eggs so they can be fertilized in the laboratory with your sperm. The embryos created are transferred to her uterus.
- **Testicular sperm extraction (TESE)**—If no sperm are present in your semen, this surgical procedure performed under anesthesia can be considered. The doctor removes pieces of tissue from your testes, which are then examined for mature sperm. If sperm are found, your female partner can undergo an IVF cycle to remove mature eggs so they can be fertilized in the laboratory with your sperm. The embryos created are transferred to her uterus.
- **Donor sperm**—Sperm donated by another man are used to produce a pregnancy through artificial insemination.

Options for Females

- **Use of your frozen eggs or embryos**—If you froze eggs, they will first be fertilized in the laboratory with your partner's sperm to create embryos. The embryos are transferred to your uterus.
- **In Vitro Fertilization (IVF)**—If you have a low ovarian reserve (low egg count) you may want to consider undergoing an IVF cycle to remove mature eggs so they can be fertilized in the laboratory with your partner's sperm. The embryos created are transferred to your uterus.
- **Donor eggs**—Eggs donated by another woman who undergoes an IVF cycle can be fertilized in the laboratory with your partner's sperm. The embryos created are transferred to your uterus.

- **Donor embryos**—Embryos are generally donated by couples who have undergone IVF for infertility. They now have families and choose to donate their remaining embryos rather than discard them. The embryos are transferred to your uterus.
- **Surrogacy**—If you are unable to carry a child, you can arrange for another woman to carry for you. She is called a gestational carrier. Embryos created by your eggs or donor eggs are transferred to her uterus.

Adoption

Adoption is another option for building a family after cancer treatment. In general, people who have been treated for cancer but are free of disease are eligible to adopt infants or older children. At this time adopting from within the U.S. is generally easier than adoption internationally. Policies vary from state to state and from country to country, so it is important to work with an adoption agency or attorney to guide you.

Other Reproductive Health Issues

Pregnancy

Most women of childbearing age who have been treated for cancer and are able to conceive (are fertile) can go on to have normal pregnancies and healthy babies. Women should be able to become pregnant if treatment did not affect the ovaries or uterus. Before you try to become pregnant, talk with your oncologist about your medical readiness for pregnancy. You may also want to consult with a reproductive endocrinologist for a fertility assessment.

Even though some drugs used to treat cancer, such as imatinib, are not usually associated with infertility, they are not recommended to be taken by women who are pregnant. Patients, however, should not stop medication without medical advice. A woman who is taking imatinib or any other cancer drug should consult her oncologist before trying to conceive or if she thinks she is pregnant.

Health of Children of Cancer Survivors

Most children born to cancer survivors are healthy. The percent of babies with birth defects born to cancer survivors is similar to that of babies born to parents without a cancer history.

When a parent is diagnosed with cancer, it does not mean that his or her child is at a greater risk for cancer. Very few cases of cancer are inherited (passed on from a parent to a child). You may want to ask members of your healthcare team if your cancer is a type that can be passed on to your children. If it is, you may want to ask for a referral to a genetics counselor.

Breastfeeding

Talk with the doctor about whether you will be able to breastfeed after treatment. If you have had radiation to the breast area, your ability to produce milk may be affected.

Some medicines should not be used while you are breastfeeding. Tell your healthcare team if you are starting treatment and are breastfeeding.

Birth Control and Sexually Transmitted Diseases

If you are sexually active, it is important to use birth control throughout your treatment and for a period of time after treatment ends. Some drugs can be very harmful to an unborn child and may cause birth defects.

Even if you know you cannot become pregnant or father a child, you are still at risk for sexually transmitted diseases (STDs). It is important to protect yourself from STDs. A barrier method of contraception is recommended. Ask your healthcare team members for more information.

Talking With Members of Your Healthcare Team

Ask your oncology team about the fertility effects of your treatment. By having this information before treatment begins, you can consider the options most likely to preserve your fertility. You can also ask for a referral to a fertility specialist to help you understand and explore your options. Some questions you may want to ask are:

- What are the chances the treatment will affect my fertility?
- Have other people been able to get pregnant or father a child naturally after receiving this treatment?
- What can we do to protect fertility before treatment begins, during treatment and/or after treatment ends? Can you recommend a fertility specialist that I can speak with?
- How will I know if treatment has affected my fertility?
- If I have a period of infertility after treatment, should I have my fertility status re-evaluated in the future? If yes, how soon should I have a follow-up evaluation?

Learning that you have cancer-treatment-related infertility may bring on feelings of sadness, anger, or grief. Some people find it helpful to talk about this. Consider asking your healthcare team the following questions:

- Can you suggest a local support group of people who have been through the same challenges?
- Can you recommend a mental health specialist I can speak with?

Talking With Other People

If you want to start dating, or you have just begun to date, you may be wondering how to tell someone that you have or have had cancer and if your treatment has affected your fertility. There is no right or wrong way to tell someone about your cancer history.

Whether you are the patient, partner or parent, it can be helpful to seek the support of other people. You can find support from other cancer survivors, friends, family members and support groups. Your healthcare team and The Leukemia & Lymphoma Society can help you access local or online support resources.

Financial Concerns

Fertility treatments can be expensive, so it is important to find out whether your health insurance plan covers the treatment you need. Unfortunately, many plans do not cover fertility preservation treatment. If you are denied coverage, you may be able to appeal for reimbursement.

Some questions you may want to ask an insurance professional are:

- Does my plan pay for a consultation visit with a fertility specialist?
- Does my plan cover fertility preservation before cancer treatment?
- Does my plan cover infertility treatments? If yes, what are the conditions for coverage?
- Do I need to see a doctor from a particular list of doctors (also called a network) in order to receive insurance coverage?
- Do any visits need to be pre-authorized (approved by the insurance company before the patient sees the doctor)? Do I need to complete claim forms or other paperwork?
- What is my copayment (the amount of money you pay out of pocket) for the services needed?

LIVESTRONG/Fertility (formerly Fertile Hope) offers discounted rates for fertility preservation for eligible patients who go to a participating fertility specialist (see Resources, beginning on page 6). In addition, some fertility specialists offer their own discount programs for cancer patients.

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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 website 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 publications that can either be read online or downloaded. Free print versions can be ordered. For more information, please visit www.LLS.org/publications.

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 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 with fertility concerns 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 our LLS Information Specialists who can help conduct clinical-trial searches
- Visit: www.LLS.org/clinicaltrials.

Advocacy. LLS 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

General Information on Fertility and Family Building Options

- Path2Parenthood
(888) 917-3777
www.path2parenthood.org
- American Society of Reproductive Medicine,
Reproductive Facts
www.reproductivefacts.org
- Resolve: The National Infertility Association
(703) 556-7172
www.resolve.org

Information on Fertility and Family Building Options for Patients with Cancer

- American Society of Clinical Oncology, Cancer.Net
 - Fertility Preservation—www.cancer.net/research-and-advocacy/asco-care-and-treatment-recommendations-patients/fertility-preservation
- Oncofertility Consortium at Northwestern University
 - MyOncofertility—www.myoncofertility.org
 - SaveMyFertility—www.savemyfertility.org

- American Cancer Society
 - Fertility and Women with Cancer—www.cancer.org/treatment/treatmentsandsideeffects/physicalsideeffects/sexualsideeffects/women/fertilityandwomenwithcancer
 - Fertility and Men with Cancer—www.cancer.org/treatment/treatmentsandsideeffects/physicalsideeffects/sexualsideeffects/men/fertilityandmenwithcancer/index
- For teens and parents of children
 - Teens Health—www.teenshealth.org/teen/cancer_center/feelings/fertility.html
 - Children's Oncology Group - Males
www.childrensoncologygroup.org/index.php/hormonesandreproduction/malereproductivehealth
www.survivorshipguidelines.org/pdf/MaleHealthIssues.pdf
 - Children's Oncology Group - Females
www.childrensoncologygroup.org/index.php/hormonesandreproduction/femalereproductivehealth
www.survivorshipguidelines.org/pdf/FemaleHealthIssues.pdf
- *Having Children after Cancer*, Gina M Shaw, Celestial Arts, Berkley, 2011

Financial Assistance

Fertility preservation before cancer treatment

- LIVESTRONG/Fertility—www.livestrong.org/we-can-help/fertility-services/
Arranges for discounted rates for sperm banking and for egg/embryo freezing at participating centers; provides many medications needed for egg or embryo freezing without charge.
- Heart Beat
(888) 347-3415
www.ferringfertility.com/savings/heartbeat
Provides many medications needed for egg or embryo freezing without charge.

Discounted rates for long-term storage of frozen eggs, embryos, or sperm

- Repro Tech, Verna's Purse Program—www.reprotech.com/financial-assistance.html?faqitem=faq31
- California Cryobank, Fertile Future Program—fertile-future.com

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This publication is designed to provide accurate and authoritative information in regard to the subject matter covered. The Leukemia & Lymphoma Society distributes it as a public service with the understanding that The Leukemia & Lymphoma Society is not engaged in rendering medical or other professional services.