



## Reproductive Questions & Answers for Cancer Survivors: A Guide for Teens

Today, more and more girls are living healthy lives after having cancer. As a cancer survivor, you may have some special concerns about your menstrual periods, fertility, and sexual relationships. This guide was created to help answer your questions about: hormones and ovaries, premature ovarian insufficiency (*POI*, formerly called *premature ovarian failure*, or *POF*), fertility and pregnancy, fertility treatments, other fertility issues, and sexual relationships after cancer.

### Hormones and Ovaries

#### What is “normal” ovarian function?

Your ovaries are a part of your reproductive system and their normal function is to release eggs and make hormones. Hormones are chemical messengers in the body that are needed for healthy growth and development in girls and women. Estrogen and progesterone are two important hormones released by the ovaries. They are the hormones responsible for healthy bones, breast growth, and regular menstruation.

#### What is “normal” menstruation?

Menstruation, or your period, happens once a month for most women. Some girls don't get their period every month, and that can be normal too. Your period will usually last between two and seven days, although it may last longer for some girls. During the first year of menstruation it is common for your period to be irregular. Stress, intense physical activity, not eating well, pregnancy, and cancer treatments can all cause you to skip your period.

#### Will my ovaries work after receiving chemotherapy?

Both the type and amount of chemotherapy that you had could affect how well your ovaries will work. Your ovaries may have been hurt somewhat by the chemotherapy that was used to treat your cancer even if you still have periods after the chemotherapy is over.

During your chemotherapy, or for a period of time after your chemotherapy has ended, it is possible that your ovaries will temporarily stop working, even if they have not been permanently damaged. If the effect of the chemotherapy is temporary, your ovaries will begin to work again (*they will make eggs*) sometime after your chemotherapy has ended.

It has also been shown that women who receive certain types of chemotherapy may go through menopause earlier than women who have never received chemotherapy. This can happen even if your ovaries were okay right after the chemotherapy treatments. This means, instead of going through menopause at the average age of 52 years old, it's possible that you may begin menopause early (*premature ovarian insufficiency*) in your 20's, 30's or 40's. This is important for you to consider when planning a family.

#### Will my ovaries work after having had radiation?

If your ovaries were exposed to the radiation that was used to treat your cancer, they may have been damaged. This is particularly true if you received radiation to your pelvis (*the lower part of your abdomen, beneath the belly button*). If you received radiation to your entire body, this will also affect your pelvis and ovaries. If you received radiation to other parts of your body, it is unlikely that your ovaries were affected.

#### If I had chemotherapy or radiation, how were my ovaries affected?

Your oncologist or gynecologist should be able to tell you if your ovaries were affected by your cancer treatment(s). Your ovaries are part of your reproductive system. They make hormones and release eggs. Generally, if the chemotherapy and/or radiation you received affected your ovaries, your ovaries will stop making hormones and eggs and you will not have a period.

In some cases, ovaries may be partially affected by cancer treatment(s). Some young woman may ovulate occasionally and have light or infrequent

periods because their ovaries are making only small amounts of hormones and some eggs.

## Premature Ovarian Insufficiency (POI)

### What is premature ovarian insufficiency (POI)?

If your doctor has told you that you have POI, your ovaries are no longer able to release hormones or eggs and you will not get your period. This condition is called premature ovarian insufficiency. Premature means, “before it is supposed to happen.” Ovarian insufficiency means that the ovaries are not working as they should be.

### What are the symptoms of premature ovarian insufficiency (POI)?

POI symptoms may include:

- Lack of development during puberty
- Amenorrhea (*no menstrual periods*)
- Decrease in breast size
- Hot flashes
- Vaginal dryness
- Mood swings
- Decreased interest in sex
- Insomnia (*not being able to sleep*)

The two most common symptoms that adolescents with POI report are lack of breast development and/or a lack of menstrual periods.

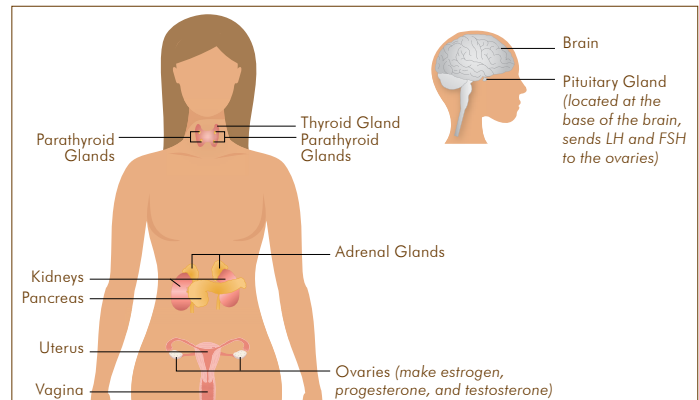
*If you think you have POI, talk to your health care provider since other medical conditions may cause the same or similar symptoms.*

### How is POI diagnosed?

Your doctor can find out if your ovaries are working by doing a simple blood test to check two hormone levels, FSH and estrogen. Sometimes it's necessary to repeat the blood test to figure out the average number or level. High levels of FSH and low levels of estrogen in a blood test usually mean that you have ovarian insufficiency.

### Why are the hormones FSH and estrogen so important?

In menstruating women, the pituitary gland in the brain can sense if the ovaries are making the right amounts of estrogen. If a woman is not getting her period and there is no estrogen being made, the pituitary gland in the brain will release a hormone called the follicle-stimulating hormone (*FSH*). This hormone sends a signal to the ovaries telling them to start making estrogen.



Your ovaries should respond to this signal and begin to release estrogen. When the estrogen is released, the pituitary gland then stops sending out FSH and the level of FSH in your blood stream lowers. However, if you have POI, your ovaries can't make estrogen so the amount of FSH in your blood stays very high.

### Is POI permanent?

POI can be unpredictable. After treatment for cancer, you may or may not get back regular menstrual cycles and ovarian function. It is possible to have POI after cancer treatment but later have your ovaries return to making hormones and possibly eggs. Unfortunately, there is no available test at this time for health care providers to tell for sure if POI will be permanent.

### How is POI treated?

The treatment for POI is to replace the hormones your body is no longer making. The name for this type of treatment is called hormone replacement therapy, or HRT. The hormones that need to be replaced are estrogen, progesterone or both. These hormones are necessary for breast development, menstrual periods, and healthy bones.

### How do you take HRT?

There are different types of HRT. HRT is available as pills, skin patches, and shots. Pills are usually the easiest type of HRT for young women to take, although some women prefer using patches that are applied to the skin once or twice a week. A vaginal hormonal ring is another option. Birth control pills are often used as an HRT because they contain estrogen and progesterone.

*Although HRT may help to replace the hormones that your ovaries don't make anymore, there is no way to replace your eggs if they have been damaged by cancer treatment.*

## What are the effects of Hormone Replacement Therapy (HRT)?

Your breasts may increase in size if they have not finished growing. You may start having menstrual periods if your uterus is healthy. You may get PMS, menstrual cramps, irregular menstrual periods, or mood swings, just like you would if your body was making the progesterone and/or estrogen.

If you are having any side effects from the HRT, it is important to discuss them with your health care provider. There are many different types of HRT, and your provider can work with you to find the one that is best for you.

## Fertility and Pregnancy

### If I am planning to receive chemotherapy or radiation therapy, is there anything that I can do to increase my chances of being able to get pregnant in the future?

Yes. The goal of treatment is to keep your ovaries safe from the possible side effects of chemotherapy and/or radiation. Although there are limited scientific studies, early findings suggest that either a surgical procedure to move the ovaries out of the field of radiation or medicine that temporarily turns your ovaries off and keeps your eggs safe may be effective in increasing your chances of becoming pregnant later. Everybody is different and factors such as your age at treatment, kind of cancer you had, and type of treatment you received will determine what treatment option your gynecologist or reproductive endocrinologist recommends for you.

**Freezing of ovarian tissue** – Some fertility centers are able to freeze ovarian tissue. This has had limited success but may be an option for some young women.

**Freezing eggs** – This requires a procedure to remove the eggs from you and then freeze them. Just like chicken eggs, human eggs are hard to freeze. Success is limited. The medical term for this is “oocyte” (egg) “cryopreservation” (freezing) of a human egg. There are some problems with this method and generally two weeks of injected hormonal medications are needed in order to remove eggs from the ovaries, but success with cryopreservation has been increasing.

**Oophoropexy** – This is a surgical procedure that is done to move one or both of the ovaries away from where the radiation is pointed. This procedure used to be done by making an incision or cut across the lower part of the abdomen or belly. A procedure called a laparoscopic oophoropexy is often recommended because the incision is much smaller and the recovery time is much quicker.

**GnRH agonists** – This is a man-made hormone and medical treatment that works by temporarily shutting off your ovaries which causes symptoms similar to menopause. This medicine is available in a nasal spray or injection. GnRH agonists work by lowering the estrogen level and stopping the eggs in the ovaries from being stimulated. Most women will not have periods while taking this therapy, however, some side effects of treatment may include irregular vaginal bleeding, depression, headaches and/or insomnia. Usually a woman will start to ovulate again and get her period about 6 weeks after stopping this medicine. Some studies have shown that women who receive GnRH agonists while on chemotherapy have a better chance of preserving their ovarian function.

**Oral Contraceptive Pills (OCPs)** – Some gynecologists feel that OCP's may have a protective effect on fertility. This is based on a small research study that compared the amount of “follicles” or young “eggs” a woman has before and after chemotherapy. Early findings suggest those women, who were taking OCP's during chemotherapy, had the same amount of follicles (young eggs) before and after treatment.

*Talk with your doctor about what option to preserve your fertility is best for you, before you plan to receive cancer treatment.*

### If I had chemotherapy or radiation, will I be able to get pregnant?

If chemotherapy or radiation has not affected your ovaries or uterus, then you should be able to get pregnant. If chemotherapy or radiation has affected your uterus and ovaries then you will need the help of special fertility treatments to become pregnant.

*If you are planning to become pregnant, then like all women, you should start taking a daily multivitamin that contains folate.*

## Fertility Treatments

### In-vitro Fertilization (IVF) with your own eggs

This type of IVF involves fertilizing your eggs with your partner's sperm in a laboratory environment after you have received injections of fertility medicine. These fertilized eggs or embryos, are then put back into your uterus. Otherwise, they are frozen and kept in the lab until you are ready to become pregnant. At that time, the frozen embryos (*fertilized eggs*) are thawed and then put into your uterus where one of the eggs has the potential of developing into a baby.

You can only use your own eggs if they are removed and fertilized before your cancer treatment begins. Human eggs can be frozen and fertilized later however this method has had poorer success.

### IVF – with donor eggs

This is done by removing another woman's egg from her ovary, fertilizing it with your partner's sperm, and putting that fertilized egg into your uterus. You would then carry and give birth to the baby. This type of fertility treatment is offered to women who have POI (premature ovarian insufficiency) and do not make eggs. Your uterus (*womb*) will be able to carry a baby even if you have POI, unless you were treated for a Wilm's tumor or received high doses of radiation directly to your vagina or uterus.

### Gestational Carriers

If, as a result of your cancer treatment, your ovaries are still healthy but your uterus is not, it is possible to have another woman (*called a gestational carrier*) carry a baby that comes from one of your eggs. In this case, an egg would be removed from your ovary and fertilized by your partner's sperm in a lab. The fertilized egg would then be implanted into the gestational carrier's uterus, and she would carry the baby until birth. Before the baby's birth, you would then be able to work with a lawyer so that the child will be yours both legally and genetically. If both your ovaries and uterus are damaged, you can also use a gestational carrier with donor eggs and your partner's sperm.

### Adoption

This is another important option for young women who have POI. There are many children who need a home and are adopted by couples or single women who can't have their own children.

## Other Fertility Issues

### If I get pregnant with my own eggs after cancer treatment, will my baby be normal?

Yes! Your chance of having a normal baby is the same as other women your age.

### Should I expect any problems with my pregnancy or breast-feeding since I had cancer?

In most cases, women who become pregnant after cancer treatment are able to have normal and healthy pregnancies. In some studies, women who had high amounts of radiation to their pelvis had higher rates of miscarriages (*the fetus died*) or early births. Every woman's pregnancy is different and should be followed closely by her health care provider regardless of whether or not she has received cancer treatment.

Your ability to breast-feed your child after your pregnancy will not be affected unless you have received radiation treatment to your breast area or head during your cancer treatment. Although the breast that received radiation will most likely produce little or no milk, you will still be able to feed your baby with the other breast if it was not exposed to radiation.

### Is there a chance that my children will get cancer too?

While some cancers run in families, most cases of cancer are caused by something random and do not increase the risk of cancer for other family members. Only 5–15% of all cancer cases has something to do with a gene that you inherited. Most cancer survivors have healthy children. If you have concerns, you should talk to a genetics counselor.

### Who can I talk to about fertility issues?

The first person you should talk to about fertility issues is your gynecologist or a reproductive endocrinology specialist. He or she will be able to figure out what kind of effect your cancer or cancer treatment has had on your ovaries and uterus. If needed, your gynecologist can refer you to a fertility specialist who can help you with your options.

### What are the chances that my cancer treatment caused my infertility?

Infertility is a common problem that affects millions of couples in the world. It may be difficult for your doctor to tell whether your infertility is a result of your cancer treatment or a condition that existed before your cancer.

## The chances that you are infertile because of cancer treatment depend on a few factors:

- **Your age at treatment:**

Girls who are treated in childhood usually have fewer reproductive problems than those who are treated in their teen or adult years. Also, older women are more likely to be infertile and have POI. This is because girls are born with all the eggs that they will ever have. The older you are, and the more menstrual cycles you've had, the fewer eggs you have left. Younger girls have a larger supply of eggs and may be able to finish cancer treatment with some eggs still remaining in their ovaries.

- **The kind of cancer you had:**

Some cancers need treatments that are more harmful to your reproductive organs than others. An example of this would be a cancer that requires either surgery on your pelvic organs or direct radiation to your pelvis.

- **The kind of treatment you received:**

Some cancer treatments, such as bone marrow transplantation, cause high rates of infertility. If you received large amounts of radiation to your pelvis (*for treatment of Wilm's Tumor, for example*), there is a good chance that your ovaries were affected. Low amounts of radiation to areas of your body not near your reproductive organs are less likely to cause infertility.

## Sexual Relationships After Cancer

### Will I be able to have a normal sex life?

Most likely the answer is yes. However, cancer survivors often face psychological issues because of their struggles with cancer. Therefore, having a sexual relationship might involve thinking a lot about your inner feelings and sharing with your partner how cancer has impacted you emotionally. Many cancer survivors have difficulty with their body image. Treatment for cancer may have left you with scars from operations, a loss of body weight, a loss of parts of your body (*such as a breast, arm, or leg*), or other physical changes. You may have fears and anxieties about sharing your new body with a partner, and about what his or her response might be. Talking with your partner and telling him or her about your fears may help you to better understand each other.

### Is it normal for it to take a long time before feeling comfortable in a relationship?

Yes. Some cancer survivors worry about being "abnormal," or different, in their social and sexual

development because of the struggles they've been through. Because of this, you might have a hard time getting comfortable in your relationships, or you could find it difficult to discuss with your partner what you want in a relationship. It is important to remember that lots of girls who have not had cancer feel better moving at a slower pace for many different reasons. There is no reason to rush your relationship, and you should take as much time as you need to feel comfortable with your partner. There is nothing wrong with taking your time!

### What physical problems might I have with intercourse?

Some cancer survivors may have sexual problems because of their cancer treatment. These include a lowered sexual response, pain, vaginal dryness, and less of an interest in sex. Surgery that has changed the size or shape of your vagina may cause difficulty with intercourse. In addition, if you have POI, you might have vaginal dryness and less of an interest in sex because of low hormone levels. Vaginal dryness can cause pain with intercourse, but vaginal lubricants such as K-Y Jelly™ or AstroGlide™ often help with this problem. If you take HRT (*Hormone Replacement Therapy*), it is likely that most of these symptoms will go away.

### Should I tell my partner about my cancer?

Sharing information about your cancer with a romantic partner is a very personal decision. It is a difficult one to make because it's hard to know when the time is right to bring it up. Some girls worry that their partner will find them less attractive if they find out about their cancer, or that the news will "scare them away."

You should talk about your cancer when you feel ready and comfortable with sharing it. Your partner will not be able to tell from having intercourse with you that you have had cancer. However, if you have had surgery on your vagina you might have physical changes that your partner could have questions about, and you may want to prepare some answers.

*In recent years there has been a great improvement in the survival rates for girls and women who have had cancer. Your quality of life after surviving cancer is extremely important. Be sure to take care of yourself! If you have any concerns, be sure to talk with your doctor or nurse so that all of your questions are answered.*