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## Late and Long-term Effects of Cancer

You might not think much about late or long-term side effects during cancer treatment. You might be just trying to survive day-to-day, which is a normal response for someone with cancer. But it's important to know the late and long-term side effects you might experience because of your cancer treatment.

- [What are late and long-term side effects?](#)
- [Common late and long-term side effects of cancer treatment](#)
- [Questions to ask](#)
- [Learn more: Children, teens, and young adults](#)

### What are late and long-term side effects?

Side effects include the unintentional, unexpected, or unwanted effects of cancer treatment.

**Late side effects** are ones that start after treatment ends. These side effects can happen months or years after cancer treatment.

**Long-term (or chronic) side effects** are ones that start during treatment but continue even after treatment is over.

It's hard to say who will have late or long-term side effects and who won't. Most of the time, there isn't one single reason. It's more likely a combination of reasons, such as:

- The type and dose of cancer treatment you received.
- If you had side effects during treatment, and how severe those side effects were.
- Health problems you had before treatment (known or unknown).
- Your ability to follow survivorship recommendations (such as lifestyle habits, cancer

- screening, ) after cancer treatment.
- Quality of survivorship care (knowledge and skill of your health care team of cancer survivorship care).
  - The level of support you get from others during and after treatment.

## Common late and long-term side effects of cancer treatment

There are many possible late and long-term side effects from cancer treatment. Some of this depends on which type of treatment you have and the doses you get. The side effects listed below are the most common.

### Cancer-related fatigue

Fatigue is the most common long-term side effect of cancer treatment. **Cancer-related fatigue (CRF)** is different than being tired. It might not improve much or at all with rest. Many cancer survivors have fatigue for months or even years after cancer treatment.

Learn more about [cancer-related fatigue](#)<sup>1</sup> and how to manage it.

### Bowel or bladder problems

Cancer treatments that damage your bowel or bladder can cause long-term or late side effects. The most common causes of this are surgery and radiation to the abdomen (belly) or pelvis.

Common bowel and bladder problems include:

**Bowel dysfunction (not fatigue) caused by scarring (adhesions)** (caused by treatments in the abdomen (belly) or pelvis)

pain, medicines, caffeine, shift work, and coping methods can all cause sleep problems after cancer treatment.

If you have sleep problems, working on these different causes is often the best place to start. It's also important to have good sleep hygiene. Sleep hygiene includes habits or routines that promote quality sleep such as going to sleep and waking up around the same time every day or avoiding screens an hour before bed.

Learn more about [managing sleep problems](#)<sup>3</sup>.

## **Mental distress**

Many people who go through cancer say they weren't prepared for the late and long-term mental health effects.

The most common types of mental distress among cancer survivors are:

- Anxiety
- Depression
- Post-traumatic stress and PTSD
- Loneliness
- Fear of recurrence

Learn more about [managing your emotional and mental health](#)<sup>4</sup> after cancer treatment.

## **988 Suicide & Crisis Lifeline**

988 Suicide & Crisis Lifeline provides 24/7, free and confidential support via phone or chat for people in distress, resources for you or your loved ones, and best practices for professionals. Includes information on finding your local crisis center.

**Phone:** 988

- Interpretation for more than 240 languages
- ASL Videophone for people who are deaf or hard of hearing

**Text:** 988 (English and Spanish only)

**Website:** <http://suicidepreventionlifeline.org><sup>5</sup>

To get immediate help, you can also go to the emergency department or call 911.

### **Changes in memory, thinking, and focus**

Some people call this type of side effect chemo brain, but changes in memory, focus, and thinking can also be caused by other types of cancer treatment (such as radiation to the brain). The medical term for these changes is cognitive impairment. Make sure your doctor knows about any changes you have in memory, thinking, or focus. If you have new or worsening changes, tell your doctor right away. These could be signs of a more serious problem.

Learn more about [changes in memory, thinking, and focus](#)<sup>6</sup>.

### **Hearing changes**

High doses of chemotherapy (especially ones that are **platinum-based**) and radiation to the head, ear, or brain can cause damage and hearing problems in one or both ears. Certain antibiotics (medicines for infection) and non-chemo medicines can also cause hearing loss.

Hearing loss related to cancer treatment is often permanent (doesn't go away), but a hearing aid might help.

### **Vision changes**

Certain cancer treatments and medicines can cause changes in your vision (eyesight). They can also cause eye conditions such as cataracts and glaucoma.

Other possible late and long-term side effects to your eyes include dryness, redness, swelling, sensitivity, or irritation.

If you have, or had, vision changes from cancer treatment, ask your health care team about seeing an ophthalmologist (a doctor trained to treat people with eye conditions).

### **Endocrine or hormone problems**

Some types of cancer treatments affect parts of the body that make hormones. This can lead to health problems depending on what hormones are affected.

#### ***Thyroid hormones***

Certain cancer treatments can damage the thyroid gland, the gland which makes thyroid hormone.

Treatments that can damage the thyroid gland:

- Radiation therapy to the head and neck (most common)
- Surgery to remove your thyroid gland (thyroidectomy)
- Total body irradiation (TBI)
- High doses of chemotherapy
- Certain types of immunotherapy and targeted drug therapy
- [Radioactive iodine](#)<sup>7</sup> used for certain thyroid cancers

Most thyroid problems related to cancer treatment are due to low levels of thyroid hormone (hypothyroidism). The most common signs and symptoms of an underactive thyroid are:

- Fatigue or sleep problems
- Hair loss
- Dry skin
- Muscle cramps
- Anxiety or depression
- Feeling more cold than usual

People treated for thyroid or head and neck cancers have the highest risk for thyroid problems after cancer treatment. Your doctor might want to check your thyroid levels every so often. If you do have hypothyroidism, it's usually easy to manage by taking a thyroid replacement medicine.

### ***Androgens (sex hormones): Estrogen***

Some cancer treatments affect the ovaries, which help make the hormone **estrogen**.

Treatments that can affect the ovaries:

- Surgery to remove ovaries (oophorectomy)
- Radiation to the ovaries or pelvis
- Medicines that temporarily stop the ovaries from making hormones
- Steroids

These treatments can cause symptoms of menopause, especially hot flashes, bone loss, and changes in libido (sexual desire).

Symptoms of menopause caused by cancer treatment may be worse than symptoms of natural menopause. This is because there is a sudden stop of hormones instead of a natural decrease over time.

If you haven't gone through menopause yet, your menstrual periods might be lighter or happen less often. Some people stop having periods altogether. If your cancer treatment only blocks hormones temporarily, your periods might come back after treatment.

Most people over the age of 40 don't start menstruating again after treatment ends.

### ***Androgens (sex hormones): Testosterone***

Some cancer treatments affect the testes, which help make the hormone **testosterone**.

Treatments that can affect the testes:

- Surgery to remove testes (orchiectomy)
- Radiation to the prostate or pelvis
- Medicines that temporarily stop the testes from making hormones
- Steroids

These treatments can cause symptoms such as hot flashes, difficulty having or keeping an erection, changes in libido (sexual desire), bone loss, and weight gain.

People with testicular or prostate cancer have the highest risk for hormone problems related to cancer treatment.

### **Problems with sexuality and fertility**

Studies show that health professionals don't always ask or talk about the sexual and fertility side effects that certain cancer treatments can cause.

If you have concerns about sexuality or fertility after cancer treatment, you might need to be the one to start the conversation with your health care team. If you aren't getting the information you need, you can always ask if a referral to a specialist might help.

## ***Fertility***

Any cancer treatments that affect the reproductive system can cause fertility problems. Certain types of chemotherapy and radiation to the pelvis or abdomen (belly) can damage the ovaries and testes.

Sometimes fertility problems are temporary (short-term) and get better over time. Others can be permanent (long-term). This depends on the type of treatment. Fertility problems can affect anyone, no matter their sex. Cancer treatments are more likely to affect fertility when they are given during or after puberty.

Some people choose to do fertility preservation before cancer treatment. Fertility preservation includes different methods of collecting or protecting a person's reproductive tissues or organs. Learn more about [fertility preservation and cancer](#)<sup>8</sup>.

## ***Sexuality***

Sexuality is more than just sex. There are five parts:

1. **Sexual health** includes sexual relationships, contraception (birth control), and sexually transmitted infections (STIs).
2. **Sexualization** includes how we use our sexuality via messages, flirting, or controlling others. Sexualization is also affected by sexual abuse and trauma.
3. **Intimacy** includes how close we feel to someone (not just physical or sexual).
4. **Sexual identity** includes both gender identity and sexual orientation.
5. **Sensuality** is how aware and accepting we are of our bodies.

Many people don't get enough information or support to deal with the effects of cancer treatment on their sexuality. Some people might think it's silly to worry or ask about sexual problems because compared to having cancer, it's not "iGS253 jT 1 0 Oility

Learn more about [how cancer treatment can affect sexuality](#)<sup>9</sup>.

## Bone problems

The inside of bone is spongy, with holes. As we get older, these holes get larger, and our bones become less dense. This makes them more likely to break or fracture. Cancer treatment that affects your hormones can also make your bones less dense, or weaker.

Your health care team might send you to get a special type of x-ray to check this. The x-ray is called **dual x-ray absorptiometry** or a **DEXA scan**.

A DEXA scan will



risk for cavities and tooth loss.

### ***Osteonecrosis of the jaw (ONJ)***

Osteonecrosis of the jaw (ONJ) is a rare but serious side effect of certain cancer treatments. It happens because of poor blood flow to the jawbone. Without blood and oxygen, bone cells in the jaw start to die and can become exposed (or show through) the gums.

Cancer treatments that can cause ONJ:

- Radiation to the jawbone
- Certain medicines used to prevent bone loss or osteoporosis, called **intravenous (IV) bisphosphonates**. IV bisphosphonates can also be used to help with bone pain caused by bone metastases (when cancer spreads to the bones).

### ***Lowering your risk for teeth and mouth problems***

There are several ways to lower your risk for teeth and mouth problems. This includes:

- Good oral (mouth) care. This includes your mouth, teeth, and gums. Good oral care is very important during and after cancer treatment.
- Regular dental checkups and teeth cleanings.
- Taking steps to prevent or manage [dry mouth](#)<sup>10</sup> (xerostomia).

### **Lymphedema**

Lymphedema is a type of swelling that can develop if you've had lymph nodes removed or damaged. Lymphedema can start at any time, even years after cancer treatment. It's usually reversible if it is managed early, before it gets severe. Surgery and radiation that damages or removes lymph nodes is the most common cause of lymphedema in people who go through cancer treatment.

Lymphedema is most common if you've had surgery or radiation for breast, head, or neck cancers. It can affect your mobility, self-image, and quality of life. It also increases your risk of a serious skin infection called cellulitis.

Learn more about [preventing and treating lymphedema](#)<sup>11</sup>.



## Second cancers

Many cancer survivors say their biggest fear is getting cancer again.

Even though second cancers are not common, certain cancer treatments increase your risk for a [second \(or secondary\) cancer](#)<sup>12</sup>.

Secondary cancers are different from [cancer recurrence](#)<sup>13</sup>. Cancer recurrence is when the first, original cancer returns. A secondary cancer is when you get another, new cancer. Both secondary cancers and cancer recurrence can happen in the same or different part of the body as the first cancer.

Secondary cancers aren't always related to cancer treatment. Some people may be at risk for other types of cancer because of their family history, lifestyle, or environment.

Learn more about [second cancers related to treatment](#)<sup>14</sup>.

## Questions to ask

If you are in the middle of cancer treatment, or if you haven't started treatment yet, ask for a copy of your **treatment plan**. This is a paper that has the names of your cancer treatment, the dosage (how much), and the number of treatments or cycles planned.

If you have finished cancer treatment, ask for a copy of your **treatment summary**. This usually includes the treatment plan information as well as any issues or side effects that you had. Your treatment summary might be included as a part of your [survivorship care plan](#).<sup>15</sup>

No matter where you are in your cancer treatment, here are questions you might want to ask your health care or cancer care team:

- What are the possible long-term and late side effects of my cancer treatment(s)?
- Do I have a higher risk for certain side effects?
- Is there anything I can do to prevent or manage late and long-term side effects?
- Could these cancer treatments affect my ability to have a child (fertility)?
- Do these cancer treatments increase my risk for any other cancers (second cancers) later in life?
- Which [cancer screening tests](#)<sup>16</sup> should I get and how often?
- What other specialists (such as a cardiologist or endocrinologist) or follow-up care should I have to prevent or manage late and long-term side effects?



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14. [www.cancer.org/cancer/survivorship/long-term-health-concerns/second-cancers-in-adults/treatment-risks.html](http://www.cancer.org/cancer/survivorship/long-term-health-concerns/second-cancers-in-adults/treatment-risks.html)
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19. [www.cancer.org/cancer/types/cancer-in-adolescents/late-effects.html](http://www.cancer.org/cancer/types/cancer-in-adolescents/late-effects.html)
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