

Name: \_\_\_\_\_

MR#: \_\_\_\_\_

## Your Summary

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Your personalized OncoLife™ Survivorship Care Plan gives you information about the health risks you may face as a result of cancer therapies. Your level of risk can vary based on the doses and duration of your treatment and the combination of treatments received.

You should discuss this plan with your oncology team to better understand your personal risks. These results can be concerning, but not every survivor experiences every side effect, and some survivors do not experience any long-term effects. Learning about these risks can help you develop a plan with your healthcare provider to monitor for or reduce your risk for these side effects through screening and a healthy lifestyle.

The information in your plan is broken down by:

- Cancer therapies you received and related risks
- Future screening recommendations
- Healthy living tips
- Psychosocial issues you may face

You may see a particular side effect in more than one section because more than one therapy can cause the same long-term effect.

The information in this plan is based on the available research and literature concerning cancer survivors. This area is continually growing, and as new information becomes available, it will be added to the program. You may want to redo your plan periodically.

## You received the following treatments for Breast Cancer

- Lymph Node Removal (Dissection)
- Mastectomy
- Bevacizumab (Avastin®)
- Anastrozole (Arimidex®)
- Had Stem Cell BMT Autologous
- Radiation treatment for breast cancer after lumpectomy
- Radiation for metastasis to the brain or spinal cord
- Radiation for metastasis to the lung
- X-ray based - Conformal Radiotherapy

## Coordinating Your Care

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As a survivor, it is important that you keep a journal or notebook of your care. Include your doctor's contact information, a list of past and current medications, therapies received, laboratory and radiology studies. (Visit the [OncoPilot](#) section on OncoLink for forms you can use to organize this material). While some survivors continue to see an oncologist, many return to a primary care provider or internist for routine care, many of whom are uncertain how to care for you. Developing the OncoLife™ Survivorship Care Plan can help you and your primary care provider understand what issues to look for, and how to handle them.

If you are being followed only by a primary care practitioner, it is a good idea to maintain a relationship with an oncologist or late effects clinic, should you need any guidance or referrals with regards to late

effects. Call the cancer center where you were treated to ask if they have a survivor's clinic, or find one by searching [OncoLink's Survivorship Clinic List](#) (though this list is not exhaustive). A survivorship clinic will review the therapies you received, discuss your risks with you, and act as a consultant to your primary care team. Your OncoLife™ Survivorship Care Plan includes a "Healthcare Provider Summary" (found on the right side of your results), which is an abbreviated summary of recommendations that you can give to healthcare providers for reference.

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## Follow Up Care For Breast Cancer

After receiving treatment for breast cancer, it is important for you to adhere to your provider's plan for follow-up care. General recommendations for follow-up care include:

- Survivors who have had breast-conserving surgery (lumpectomy) or single mastectomy should have a mammogram annually. In addition, breast MRI may be considered for survivors at high risk for cancer in the other breast.
- Those who have had double mastectomy generally do not need mammograms, but you should examine your chest wall for swelling or rash, and report any changes to your oncologist.
- If you have had breast-conserving surgery (lumpectomy) and radiation, you should wait 6-12 months after radiation before beginning annual mammograms.
- Survivors should be seen by their oncologist 1-4 times per year for 5 years, and then annually after 5

years.

- If you are taking tamoxifen and still have your uterus, you should be seen once a year by a gynecologist or women's health provider for an exam. Report any vaginal bleeding to your provider immediately, as this can be a sign of uterine cancer.
- Survivors taking an aromatase inhibitor or who go into menopause due to treatment should have their bone health evaluated by a DEXA scan at baseline and then periodically thereafter as both of these can lead to loss of bone strength.
- Your team may recommend you take supplemental calcium and vitamin D.
- Routine lab testing, CT scans, or bone scans to look for cancer spread (otherwise known as metastases) are *not* recommended. Research has shown that if a woman does develop metastatic disease, the type of treatment, response to treatment, and overall survival are equivalent, regardless of if it is found before symptoms develop. In other words, outcomes are similar for those who are treated for metastases found on routine scans (with no symptoms present) and women who are not treated until those metastases cause symptoms. Therefore, providers do not routinely screen patients for metastatic disease unless they have developed symptoms.
- Research has shown that leading an active lifestyle and maintaining a healthy weight, with a body mass index (BMI) of 20-25, may result in a lower risk of recurrence. Weight-bearing exercises, such as walking, yoga, and dancing, can also help maintain bone strength. Talk with your healthcare team about resources to get started (or back to) a healthy lifestyle!
- Report any new, unusual, and/or persistent symptoms to your care team.

## Surgery Side Effects

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### Lymph Node Removal (Dissection)

The removal of lymph nodes from the axilla (underarm), abdomen, groin, or head and neck area can lead to issues with the normal draining of the lymphatic system. This can cause lymphedema, a swelling in the area/limb near the area where lymph nodes were removed. Having had radiation therapy to the area where lymph nodes were removed increases your risk of lymphedema.

Signs of lymphedema include any of the following in the limb/area where the lymph nodes were removed:

- Full, tight, or heavy feeling.
- Skin changes (reddened, warm, cool, dry, hard, stiff).
- Aching/discomfort.
- Less movement/flexibility in nearby joints.

You may also notice that you are having trouble fitting into clothes, like the sleeve of a jacket or pant leg, or feel your socks are too tight. You also may notice jewelry feels tight, even though you have not gained any weight.

Lymphedema can occur right after treatment, weeks, months, or even years later. You should watch for and report early signs of swelling. A Certified Lymphedema Therapist should be consulted at the first sign of swelling so that treatment can be started.

Reducing the demand on your remaining lymph system can reduce your risk for and control lymphedema. Do this by:

- Avoid infections, burns, cuts, excessive hot/cold, or injury to the part of the body at risk.
- Avoid insect bites by using insect repellent.
- Use lotion to prevent dry, chapped skin. Keep skin clean.
- Use sunscreen with SPF 15 or higher, seek shade, and try to avoid the sun during the hottest time of day.

- Avoid tight-fitting clothes and jewelry.
- Whenever possible, avoid using the affected arm to have blood drawn, IVs placed, shots/vaccinations given, and blood pressure taken.
- For more information on what you can do to reduce risk, refer to the article [“Understanding and Decreasing Lymphedema Risk”](#) on the OncoLink website.

Maintaining an optimal weight through a healthy diet and exercise can reduce your risk of lymphedema. If you want to start an exercise plan, talk with your care team and work with a physical and/or lymphedema therapist to create a workout plan appropriate for you. Gradually build up the amount and intensity of your exercise and monitor the at-risk areas for any changes or swelling.

In some cases, surgery to remove the lymph nodes can result in injury to the nerves in that area. Nerve damage can cause pain, numbness, tingling, decreased sensation or strength in the area or limb. This type of pain is called nerve pain and is treated with different medications than other types of pain. Speak with your care team if you are having this type of pain. Nerve injuries can be aggravated by scar tissue after radiation therapy or surgery, which can form over the months and years after treatment.

After lymph node removal, there is also a risk for [axillary web syndrome](#) (AWS). This is also known as cording. It happens when a fibrotic band or rope/cord-like texture develops under the skin. You can usually feel these rope/cord-like areas under your skin. It can cause difficulty raising your arm above your shoulder or doing overhead activities. Ask your provider for a referral for physical therapy to help you regain function.

### Key Takeaways

- Report any signs of swelling in the at-risk part of your body to your healthcare provider promptly. A Certified Lymphedema Therapist should be consulted at the first sign of swelling so that treatment can be started.
- Follow the instructions given to you to decrease the risk of developing or worsening lymphedema.

## Mastectomy

A mastectomy is the removal of the entire breast. If you choose, breast reconstruction can be done by a plastic surgeon. There is a risk of nerve damage during breast surgery. This can lead to pain in the chest wall and/or pain and tingling in the arm/hand on the side of the surgery. This pain can worsen if scar tissue forms from the surgery or radiation therapy to the area. Scar tissue can develop years after therapy. Neuropathic (nerve) pain is often described as burning or electric and can also include numbness, tingling and decreased strength or sensation. Talk to your care team if you are experiencing pain.

You may also have lymph nodes removed during surgery. The removal of lymph nodes increases the risk of developing lymphedema. Lymphedema is swelling of an extremity caused by damage to the lymphatic drainage system. Signs of lymphedema include

- Swelling (clothing or jewelry feels tight).
- Feeling of fullness or tightness.
- Aching pain.
- Limited range of motion.

Contact your care provider at the first sign of lymphedema so that treatment can be started.

If you have had a lymph node dissection and have difficulty moving the arm and/or shoulder, notify your provider. This can be temporary but could become permanent. A physical therapist can recommend exercises to promote shoulder mobility.

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happens when a fibrotic band or rope/cord-like texture develops under the skin. You can usually feel these rope/cord-like areas under your skin. It can cause difficulty raising your arm above your shoulder or doing overhead activities. Ask your provider for a referral for physical therapy to help you regain function.

Mastectomy can also bring about changes to how you feel about your body, your appearance and your self-image, regardless of if you chose to have reconstruction or not. You may also have concerns about intimacy. These are all normal feelings. You may experience feelings of sadness and grief over the loss your body has experienced. These emotions, when not addressed, can lead to depression and anxiety. Ask your provider for referrals for counseling and potentially couples/sex-focused therapy.

### **Key Takeaways**

- Report any signs of swelling in the arm/hand on the side of your surgery. You should be seen by a certified lymphedema therapist if you develop any signs of swelling.
- If you had a single mastectomy, you should have a mammogram on your remaining breast each year.
- Report pain in the breast or chest wall to your healthcare provider.
- Ask for a referral for physical therapy if you are having trouble moving your shoulder.

## **Risks Related to Medications**

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### **Autologous Stem Cell or Bone Marrow Transplant**

During an autologous (auto) transplant, very high doses of chemotherapy are used to treat your cancer. These high doses of medications can lead to side effects that can occur months to years after transplant.

While your risk for some complications is lower after an autologous transplant than an allogeneic (cells from a donor) transplant, you should still have them on your radar screen. These include:

- Pulmonary (lung) problems (pneumonia, fibrosis/ scarring, and bronchiolitis obliterans syndrome).
- Dental and oral health complications.
- Changes in hormonal function.
- Decreased kidney function.
- Vascular disease (stroke, heart attack, blood clots, peripheral artery disease).
- High blood pressure.
- High cholesterol.
- Diabetes.

Your healthcare provider will do blood and urine tests to look for these problems. They will check your blood pressure, heart, and lungs at your visits. But there are things you can do to help you reduce your risk of these and other health problems.

A healthy lifestyle is an important step in reducing your risk of many of these problems. Not smoking, getting regular exercise, and eating a healthy diet can reduce your risk of heart problems, diabetes, high blood pressure, and high cholesterol. Talk with your healthcare provider about being re-vaccinated against certain illnesses (pneumococcal pneumonia, measles/mumps/rubella, hepatitis, tetanus) after an autologous bone marrow transplant. Autologous transplant can also affect your bone health, particularly if you are a woman or have a history of lymphoma or myeloma. Your provider may order a baseline DEXA scan to evaluate your bone health one year after transplant.

### **Key Takeaways**

- A healthy lifestyle is an important part of reducing your risk for complications related to

transplant and your underlying cancer diagnosis. Avoid smoking, exercise regularly, and eat a healthy diet.

- Follow your team's recommendations for routine exams and laboratory testing.
- Have a flu shot annually.
- Talk with your health care provider about re-vaccination (pneumococcal pneumonia, measles/mumps/rubella, shingles) after an autologous bone marrow transplant.
- DEXA scans are recommended one year after transplant for patients with myeloma or lymphoma. If you have another diagnosis, talk to your provider about if you need a DEXA scan after transplant.

## Risk of Developing Osteoporosis

Osteoporosis is a decrease in bone density (thinning of the bones) that can lead to fractures (broken bones). While this information is shown under the medication or surgery tab, the risk can be related to a few things. The risk is increased for:

- People who take corticosteroids for more than 2 months (dexamethasone or prednisone, more than 5mg per day).
- People who receive radiation to weight-bearing bones (spine, hips, legs).
- Women who develop premature (early) menopause or have their ovaries removed before menopause.
- Women who take aromatase inhibitors (anastrozole, letrozole, and exemestane).
- Pre-menopausal women who take tamoxifen.
- Men who receive hormone therapy for prostate cancer or have a testicle(s) removed (orchiectomy).
- People who have had a gastrectomy (removal of the stomach).
- People who have had bone marrow/stem cell transplants.
- Several types of chemotherapy have been found to contribute to bone loss, including Cytoxan, cisplatin, carboplatin, ifosfamide, doxorubicin, methotrexate, and possibly imatinib.
- Other factors that increase the risk of osteoporosis include being over the age of 50, smoking, drinking too much alcohol, not exercising, some chronic health conditions, and a family history of osteoporosis.

## Lowering Your Risk

There are things you can do to lower your risk of a fracture and strengthen your bones. You can learn more from the National Osteoporosis Foundation ([www.nof.org](http://www.nof.org)).

- Get 1000-1200mg a day of calcium.
  - It is best to get calcium in a balanced diet, including 4-8 servings of calcium-rich foods a day. Examples of calcium-rich foods are low-fat milk, yogurt, cheese, green leafy vegetables, nuts, seeds, beans, legumes, and calcium fortified foods and juices.
  - A dietician can provide more guidance in choosing calcium-rich foods. A good resource is [www.myplate.gov](http://www.myplate.gov).
  - If you cannot get the recommended amount of calcium in foods, take calcium supplements.
  - Your body does not absorb calcium supplements well (in food or supplements), so spread your foods or supplements out over a few times a day, instead of all at once.
  - Most calcium supplements are better absorbed when taken with food. Calcium citrate is the one exception and can be taken with or without food.
  - If you take Synthroid / levothyroxine (thyroid hormone), separate it from calcium doses by at least 4 hours.
- Get 400-1000 IU of vitamin D-3 or D-2 daily.
  - Your healthcare provider may check blood levels of vitamin D with the 25-OH Vitamin D blood test. This level combined with a look at how much vitamin D you get in your diet can help guide

- how much vitamin D you should take.
- Do not take more than 2000 IU of vitamin D3 a day, unless directed by your healthcare provider. If you take calcium or a multivitamin, be sure to check if it also contains vitamin D and subtract this amount from what you need to take.
- You can take vitamin D supplements with or without food.
- Weight-bearing exercise and strength training can improve your bone strength. It can also help with other symptoms such as fatigue and can reduce your risk of heart disease and diabetes.
  - Before you start an exercise program, check first with your care team to determine if it is safe.
  - Start with what is comfortable for you and work up to the following recommendations:
  - Get 30-40 minutes of weight-bearing exercise 3 times a week. Weight-bearing exercises are those in which your feet or legs bear your body's weight while the bones and muscles work against gravity. Examples include walking, jogging, Tai Chi, yoga, and dancing.
  - Strength training 2-3 times per week, with a day of rest in between each session. Complete 8-12 repetitions of the exercises below and repeat them two times (2 sets). Choose a weight where the tenth repetition is hard for you to complete and you can't complete an 11<sup>th</sup> time. Now remove 1-5 pounds from that "maximum weight," and use that as your training weight. When you can easily do 12 repetitions, try to increase the weight by 3-5lbs.
    - Exercises include leg extensions, calf raises, leg curls, chest press, latissimus pulldown, overhead press, row machine, and curl-ups.
  - Your provider can refer you to a physical therapist or a physical medicine and rehabilitation physician for more guidance regarding bone-strengthening exercises.
- Decrease or stop caffeine intake and limit alcohol intake, as these can weaken bones.
- Quit smoking. Talk with your provider about how to get started. Learn more [on OncoLink](#).
- Your provider may order a DEXA scan, which is a test used to measure the thickness (density) of your bones.

### Key Takeaways

- Avoid smoking, caffeine, and excessive alcohol intake.
- Perform weight-bearing and strength training exercises 2-3 times per week.
- Calcium intake of 1000-1200mg per day plus Vitamin D 800iu to 1000iu per day (ideally from food sources, and supplements when your diet is not sufficient).
- Consider screening with DEXA scan.

## Understanding Chemo-Brain

Many survivors who have previously received or are currently undergoing chemotherapy or other cancer treatments report cognitive changes. This is often called "chemo-brain." Chemo-brain is not a great name for it as it can happen in survivors who didn't get chemotherapy. It is not clear what causes "chemo-brain." In addition to chemo, the cancer itself or other treatments such as hormone therapy and radiation may cause these changes.

Chemo-brain can include difficulty with short-term memory, multi-tasking, new learning, reading comprehension, working with numbers, and trouble concentrating. Many people describe it as "feeling foggy." These issues are bothersome for some and debilitating for others. These issues can improve over time for some, but many long-term survivors continue to have issues years after treatment.

A few studies have found that exercise can help with cognitive issues. Physical and occupational therapists can help get you started with exercise and help you find strategies to manage cognitive issues.

Cognitive rehabilitation programs use exercise, tasks that use memory, and puzzles to "rehabilitate" one's mind. These programs are typically used for people with brain injuries, but therapists have tailored programs for cancer survivors.



Bookstores and websites offer memory training, which may be helpful to survivors. Use tools to help your memory. Setting alarms or reminders on your phone or computer, using old-fashioned sticky notes, or making lists can all help. Working in a quiet environment without other distractions can help with concentration. Puzzles using numbers, like Sudoku, may help "exercise" your brain. Fatigue can make cognitive problems worse, so managing fatigue by getting enough sleep, incorporating exercise into your life, and eating a healthy diet may be helpful.

If cognitive issues are affecting your ability to work, look for changes in your work environment that can help. You may be entitled to "reasonable accommodations" with your employer through the [Americans With Disabilities Act \(ADA\)](#). Occupational and Vocational Rehab (OVR) programs may also be available to help assess your skills and abilities and tailor a training program to help you find work in a new field.

It is important to remember that some treatable problems can cause cognitive issues, such as thyroid problems, depression, and anxiety. If you are experiencing cognitive problems, it is important to be checked for these issues. Hypothyroidism (low thyroid hormone levels) is a common issue for survivors and can make you feel "fuzzy" or "out of it." This is easily treatable with supplemental thyroid hormone. Survivors who are depressed or experiencing anxiety can benefit from working with a therapist experienced in working with cancer patients or survivors.

### Key Takeaways

- There is no proven treatment for chemo brain, but cognitive rehabilitation/brain games, avoiding becoming fatigued, regular exercise, and a healthy diet can be helpful.
- Create reminders by making lists, using to-do apps or alarms on a phone to help you stay on track.
- If you believe you are experiencing chemo brain, you should consult your care provider to rule out other health issues including thyroid problems, depression, and anxiety.

## Fertility Concerns for Female Survivors

Fertility after cancer therapy is a very complex topic. Whether or not you will be able to get pregnant after treatment is related to:

- The doses and types of medications you received (certain medications, higher doses, or longer treatments can be more likely to cause infertility).
- If you also got radiation to the abdomen, pelvis, or brain.
- Your age at the time of treatment.
- The number of oocytes (eggs) present when therapy started. This number drops as women age and as the number of eggs drops, it becomes more difficult to get pregnant.
- Treatment that removes both ovaries or the uterus obviously has a major effect on fertility.

It is very difficult to predict if a woman will remain fertile after treatment. If your periods return after treatment, you are still at risk of going into menopause earlier than your peers. It is also not possible to predict when menopause will happen. That may also be a consideration in your family planning. For all these reasons, if you want to get pregnant, it can be helpful to be seen by a fertility specialist who has worked with cancer survivors. This specialty is often called "oncofertility." Testing can be done to evaluate your fertility, including certain hormone levels and a follicle count (a measure of a woman's remaining egg supply).

Some experts feel that women who have had cancer treatment may be at higher risk for complications during pregnancy and should consider seeing a high-risk obstetrician. This is particularly important if you received radiation to the abdomen or pelvis area, had surgery involving female reproductive organs, or if you received chemotherapy that can cause heart damage.

Certain treatments are more strongly tied to infertility, including:



- Certain anti-cancer medications: alkylating agents (Cytosan, busulfan, melphalan, BCNU), procarbazine, bevacizumab, cisplatin, and some FOLFOX regimens.
- We do not know how many of the newer treatments will affect long-term fertility.
- Total body irradiation and bone marrow transplant are considered high risk for infertility.
- Radiation fields that include a woman's pelvis or brain can affect fertility.

[LiveSTRONG](#) and The [OncoFertility Consortium](#) websites can help you find a fertility specialist. LiveSTRONG offers financial assistance to cancer survivors for fertility care. The [OncoFertility Consortium](#) and The National Infertility Association's website, [Resolve](#), offer information on fertility treatments and testing, adoption, and deciding to not have children. Resolve also offers information on individual state laws about insurance coverage for fertility treatments. If you underwent fertility preservation prior to treatment, you will need to work with a fertility specialist to get pregnant using your stored eggs or embryos.

Survivors should understand that even if your periods stopped during treatment, you may still be able to get pregnant. For this reason, if you were pre-menopausal before treatment, the use of effective birth control during cancer treatment is important. Accidental pregnancy during cancer treatment can be difficult to cope with, as it may limit the treatments available to you.

### Key Takeaways

- If you want to get pregnant, you should consider consulting with a fertility specialist familiar with cancer survivors.
- If you are pregnant, talk with your provider about whether or not you should be followed by a high-risk obstetrician.
- You should be aware that it is possible to get pregnant even after you have stopped having periods. Treatments such as chemotherapy and radiation may be dangerous to an unborn baby. Therefore, if you were pre-menopausal before beginning cancer treatment, you should use birth control during cancer treatment, even if your periods have stopped.

## Side Effects While Taking Aromatase Inhibitors

Your OncoLife Care Plan focuses on late effects of therapy or those that can occur months to years after completing therapy. Given that hormone therapy regimens can last anywhere from 5 to 10 years, we felt it was important to include some information about the side effects you may experience while taking these medicines.

Aromatase Inhibitors (AIs) commonly cause hot flashes and other symptoms of menopause, such as night sweats, vaginal dryness and forgetfulness. Some helpful tips include:

- Avoiding triggers such as warm rooms, spicy, caffeinated, or alcohol-containing foods or beverages can help reduce hot flashes.
- Drink plenty of fluids, wear breathable clothing in layers, and exercise regularly.
- For some women, certain antidepressant medications can provide relief of hot flashes.
- [Vaginal dryness](#) can make intercourse uncomfortable. Vaginal moisturizers (Replens) used several times a week and lubricants during sexual activity can be helpful. If these do not help, talk with your provider as you may be able to use a low-dose vaginal estrogen product.

About 60% of women taking AIs experience aching or pain in their muscles, joints or bones, also known as arthralgias. In some cases, this side effect is troubling enough for them to stop therapy. This pain is most common in the hands, wrists, and knees but can occur in any joints. Some women experience pain that comes and goes, but for others it is constant. Some women say the stiffness and pain are worse in the morning. The pain tends to get worse over time up until a year and then levels off and can improve.

Brisk walking and other moderate-intensity exercises can help significantly reduce muscle and joint pains. That can be difficult when you have pain. Seeing a rehabilitation physician, or physical or occupational

therapist can help you get started exercising or to help you manage the joint pain with stretching, strengthening, and bracing.

Nonsteroidal anti-inflammatory medicines (NSAIDs, ibuprofen, naproxen) can be used to reduce swelling in the joints, reducing discomfort. Other medications used to treat pain include acetaminophen and duloxetine (Cymbalta). Applying heat or wearing a brace can be helpful. Acupuncture can also be helpful.

In some cases, switching to a different AI medicine can result in less discomfort. Most importantly, talk with your oncology team if you are experiencing side effects. When side effects are well managed, you are more likely to stick with the treatment regimen and ultimately have the benefits it can offer.

### Key Takeaways

- You may experience hot flashes and other symptoms of menopause, as well as, aching in your muscles, joints or bones. Let your healthcare provider know if these symptoms become troublesome.
- Discuss side effects with your oncology team, as many of these are manageable. Optimal therapy can last 5-10 years, so management of side effects is critical to helping you stay on therapy.

## Sexuality Concerns for Female Survivors

Women of any age can have sexual concerns after cancer treatment. Do not hesitate to talk with your oncology team. Sexuality concerns are common. For many women, cancer treatment can cause the sudden onset of menopause. This sudden change in hormone levels in your body causes changes such as thinning and inflammation of the vaginal walls, loss of tissue elasticity, decreased vaginal lubrication, and this vaginal dryness can cause painful intercourse. You may experience hot flashes, mood swings, fatigue, and irritability. You may notice you have less desire for sex and difficulty achieving orgasm.

[Vaginal dryness](#) causing painful intercourse is a common concern for survivors. Some tips for managing this issue include:

- Use of vaginal moisturizer (Replens is the brand name) a few times a week.
- Use lubricants during sexual activity (water or silicone-based). There are many brands and generic options available at your local pharmacy.
- Vaginal estrogen therapy (suppository, cream, or ring used in the vagina) can be helpful. If you had a hormone-dependent cancer, you should discuss current research on using estrogen-based therapy with your healthcare team.
- Surgery and/or radiation therapy can result in scarring that can make intercourse uncomfortable. Open communication about position changes and alternative methods of expressing affection with your partner can help when resuming sexual activity after treatment.

If your sex life has been on hold during treatment and you are looking to rekindle your romance or start a new one, take steps to feel more at ease. Have a "date" with your partner to build the romance. Talk about what feels good and what doesn't.

Concerns about changes in your body, cancer recurrence, the stress and anxiety caused by cancer therapy, or changes in your relationship with your partner can all affect how you feel about your sexuality. It is important to understand that sexual activity cannot cause cancer to recur, nor can you spread cancer to another person through sexual activity. If you find that your feelings are significantly impacting your sexuality, you should talk with your healthcare team about finding a therapist experienced in helping cancer survivors.

Of utmost importance in addressing sexual concerns is communication, both between partners and between survivors and their healthcare team. Understand that these concerns are common, and

communication is the first step to finding the right solutions. Visit [OncoLink's section on sexuality](#) for more information.

### Key Takeaways

- Many anti-cancer medicines are associated with vaginal dryness, painful intercourse, reduced sexual desire, and the ability to achieve orgasm. Many of these issues are caused by the sudden onset of menopause, which can occur with cancer therapy. OncoLink's article on [Vaginal Dryness and Painful Intercourse](#) provides product suggestions and tips.
- In addition, you may experience other symptoms of menopause, such as hot flashes, mood swings, fatigue, and irritability. Research has found that exercise, yoga, and acupuncture can help lessen menopausal symptoms.
- Talk to your healthcare team about tips to manage these issues.
- Open communication with your healthcare team and partner is essential for regaining your sexuality and resolving issues. You may also consider talking with a therapist experienced in working with cancer survivors.

## What We Do Not Know

There are many medications that we do not know the long-term effects they may cause. Most cancers are treated with a combination of medicines. This can make it difficult to be certain which medication is the cause of a long-term effect. Research is continuing and new information may become available. You should periodically talk to your healthcare team about new information or look for new information on reliable internet sites. You can also create a new OncoLife care plan every few years to see if there is any new information included.

In addition, there have been many new therapies developed in recent years, including many of the biologic therapies, monoclonal antibodies and targeted therapies. We may not know the long-term effects of these medications for many years. As a survivor, you should be an active participant in your healthcare and keep an ear out for new information.

### Key Takeaways

- Many cancer treatments today have not been available long enough to know what issues they may cause in the years after treatment.
- Always let your healthcare team know if you notice any new or worsening symptoms. Remember, you know your body best.
- Periodically look for new information about your treatment and talk to your healthcare team to see if they have anything new to report.

## Side Effects of Radiation

Long term effects of radiation therapy vary greatly depending on the areas included in the field of radiation and the radiation techniques that were used, as these continue to develop and improve. One issue that is consistent across all tissues is the possibility of developing a second cancer in or near the radiation field. Secondary cancers develop as a result of the exposure of healthy tissue to radiation. Newer radiation techniques are designed to limit this exposure, but it is not always possible to prevent all exposure and still achieve the desired outcomes.

## Radiation for Breast Cancer (After Lumpectomy)

If you have had breast cancer, you are at risk of developing a second breast cancer in the remaining breast(s) or the axilla (armpit). You should have annual mammograms after your treatment for breast cancer.

Radiation to the breast may cause permanent changes in your skin, including a darkening or "tanning." Radiation may also cause difficulty with wound healing, so surgery to the breast after radiation should be done with caution.

Other long-term effects of chest radiation can include damage to the nerves, leading to pain or loss of strength or feeling in the arm on the side that was radiated. Damage to the drainage (lymphatic) system in the area can lead to chronic swelling, called lymphedema. The risk of lymphedema is highest for women who also had surgical lymph node dissections and sentinel node biopsy. The risk of lymphedema is lower in cases of sentinel node biopsy, but there is still a risk. Notify your provider if you notice any swelling. If you have lymphedema and you develop pain or redness in the arm, especially with fever, you should be evaluated right away for infection. Lymphedema should be treated by a physical therapist who specializes in lymphedema therapy.

Survivors of breast cancer, particularly left-sided breast cancer, may be at increased risk of cardiac (heart) issues. Please see the heart/ cardiovascular section for more information.

### Key Takeaways

- You should have a mammogram 6-12 months after you are done radiation treatment, and then yearly.
- If you are having arm pain, weakness, or swelling, see a physical or occupational therapist for management.
- Call your provider right away for new arm swelling, redness, or pain, especially with fever.

## Brain

Radiation to the brain can change how well your brain functions. The side effects you have depends on the area of the brain that received radiation. In some cases, the whole brain is treated. The more common side effects include:

- Short-term memory loss.
- Decline in memory, reasoning, or other thinking skills (dementia).
- Always feeling tired (fatigue).
- Having trouble concentrating or learning.
- Issues with walking and balance.

Your provider will monitor you for these issues. If you notice any changes in how your brain is working you should call your provider.

The pituitary gland is located in the center of the brain. It makes hormones that regulate how other glands work. It can be damaged when radiation is given to the brain. Weight gain or loss, changes in sexual function/libido, extreme fatigue, depression, and always feeling hot or cold are a few signs of abnormal levels of hormones. If you have any of these symptoms, you should speak with your provider. Hormone levels can be checked using a blood test.

Radiation to the brain can increase your risk of a stroke or a secondary brain cancer. If you develop sudden weakness in a part of your body, start slurring your speech or have trouble understanding those around you, you should immediately call 911. If you notice any changes in how your brain works you should contact your provider. They will determine if further testing is needed.

### **Key Takeaways**

- You may have memory loss or changes in how well your brain works. If you notice any changes in your memory, contact your provider.
- If you are having trouble walking or balancing, you may benefit from working with a physical/occupational therapist.
- If you are having any new symptoms that you suspect may be related to hormone levels, talk with your provider.

## **Spinal Cord**

Radiation to the spinal cord can cause damage to nerves. This can cause a loss of strength, feeling, or coordination of the arms or legs, paralysis, or problems with bowel or bladder control. Sometimes nerve damage can cause a sensation of electric shock spreading down the arms or legs. You may need imaging tests or to be seen by a neurologist for further workup of these symptoms.

Radiation can also cause damage to the bones of the spine. This can result in a reduction in height or change in the curvature of the spine. Radiation to these bones can also put them at risk for fracture (breaks). If you have any new back pain you should call your provider right away. You may need x-rays or other imaging tests.

### **Key Takeaways**

- You should call your provider right away if you are having any new back pain, trouble holding your bowels or bladder (incontinence), weakness, or suddenly not being able to move your arms or legs. You may need a radiology test to figure out what is causing these symptoms.
- If you are having shock-like pains in the arms or legs, your provider may suggest you see a neurologist.
- If you have any new curvature of the spine, you should be seen by an orthopedist.

## **Heart / Cardiovascular**

Radiation treatment to the chest can affect the heart. This can lead to different types of heart disease including:

- Coronary Artery Disease (CAD).
- Hypertension (high blood pressure).
- Valve Abnormalities.
- Fibrosis (when the tissue becomes scarred and cannot move as well as it used to).
- Pericarditis (inflammation of the sac around the heart).
- Myocardial Infarction (MI) (heart attack).
- Heart Failure.
- Arrhythmia (irregular heartbeat).

The risk of heart failure depends on the amount of radiation you received and what other cancer treatments you had. When planning your radiation treatment, it is designed to avoid the heart as much as possible. Unfortunately, in many cases, it cannot be avoided altogether. Because of the risk of heart disease, you should have a yearly history and physical by your primary care provider. They should listen to your heart, check your blood pressure, look for signs of heart trouble such as swelling in your legs/feet, and check your cholesterol and blood sugar levels with a blood test. Your provider should talk to you about healthy lifestyle choices including exercise, not using tobacco, and eating a healthy diet.

If you are at high risk based on your treatments, your provider may suggest an EKG and screening echocardiogram every 2 years to evaluate heart function.

Other factors that increase the risk of heart disease include:

- High cholesterol.
- Obesity
- High blood pressure.
- Diabetes.
- Smoking.
- Illegal drug use.

Asking about these risk factors can allow your provider to help you make healthy changes. Talk to your provider if you would like to learn more about healthy lifestyle changes to prevent heart disease.

### **Key Takeaways**

- At your yearly physical, your provider should listen to your heart, check your blood pressure, and you should also have your cholesterol and blood sugar levels checked with a blood test.
- If you are at high risk of heart failure your provider may suggest that you have an EKG or echocardiogram every 2 years.

## **Lung**

Radiation fields involving the lung can lead to scar tissue (fibrosis), inflammation (pneumonitis), and restrictive or obstructive lung disease. The risk for these problems is higher with higher doses of radiation, if you also got certain chemotherapies (bleomycin, busulfan, BCNU, and CCNU), and if you had part of the lung removed (lobectomy).

Survivors who have had radiation to the lung are strongly encouraged not to smoke because it can increase the risk of lung problems. If you need help quitting, contact your provider for help. If you don't smoke, you should not start.

Radiation can cause scarring in the lungs that may affect blood vessels. Damage to the blood vessels can lead to coughing up blood. If you cough up blood, you should be checked out right away by a healthcare provider, either in the office or the emergency room.

At your yearly physical your provider will examine your lungs and ask about possible symptoms (cough, shortness of breath, wheezing). You should get a flu vaccine every year and the pneumococcal vaccine. Your provider may also order a chest x-ray or pulmonary function test if you are at a high risk for lung problems or have symptoms of lung problems.

Of note, the Children's Oncology Group recommends survivors not scuba dive without medical clearance from a diving medicine specialist. There is no specific recommendation for adult survivors, but you should discuss this with your provider if you want to scuba dive.

### **Key Takeaways**

- Get a flu vaccine every year and a pneumococcal vaccine every 5 years.
- Smoking can further damage your lungs. You should not start smoking. If you do smoke, ask your provider for help with quitting.
- Contact your provider right away if you have a new or worsening cough, wheezing, shortness of breath, difficulty breathing, or if you cough up blood.

## Bone

Damage to the bone from radiation can cause small cracks (fractures) in the bone(s) that were in the field of treatment. As best you can, avoid any trauma such as falling or a car accident. If you do get hurt, you should ask your provider if any x-rays are needed to check for broken bones. If radiation is given in the area of a joint then permanent stiffness, pain, and arthritis can develop in that joint. This can be treated with medications called non-steroidal anti-inflammatories (NSAIDs) and with physical or occupational therapy.

### Key Takeaways

- If you are having pain after any trauma, such as a fall or car accident, you should be evaluated for damage to your bones.
- If you develop arthritis, you may be given medications to decrease pain and inflammation.
- Working with a physical or occupational therapist may also be helpful.

## Skin

Radiation can lead to permanent changes in the skin. There may be changes in the color or texture of your skin or new scars. It can also change the color and texture of your hair or can cause permanent hair loss in the treated area.

The soft tissue and muscles under the skin can develop scarring and/or shrinkage, which can lead to a loss of flexibility and movement or chronic swelling. You may develop chronic or recurring ulcers of the skin in the area treated. Blood vessels of the skin may become dilated and more visible, although this is not harmful.

If your skin is more sensitive after radiation, it is best to use fragrance and dye-free soaps, and moisturizers in the area. After radiation, the skin in the treated area is more sensitive to sunlight. This sensitivity will last for your lifetime. Make sure to use plenty of sunscreen, wear a hat, and keep the skin covered with clothing. Apply sunscreen 30 minutes prior to going in the sun and reapply sunscreen at least every two hours. Try to avoid being out in the sun between the hours of 10 am-4 pm when it is the strongest.

If you notice any new or worsening skin issues anywhere on your body, you should contact your provider for an assessment.

### Key Takeaways

- The area of skin that was affected by radiation may be more sensitive. The skin will likely always be drier. Care for your skin using mild soaps and moisturizers. Use sunscreen daily to prevent sunburns.
- Contact your provider if you have any changes to your skin.

## Lymph Nodes

The removal of lymph nodes can lead to lymphatic fluid not draining from the nearby area (leg, arm, neck, abdomen). This poor drainage causes a swelling called lymphedema. Radiation therapy to the same area that lymph nodes were removed puts you at greater risk of developing lymphedema. While sentinel node biopsy can decrease the risk of developing lymphedema, it does not completely eliminate the risk. Lymphedema can cause pain, disfigurement, and difficulty with daily activities. It can also increase the risk of a serious infection in that limb.

You should see a Certified Lymphedema Therapist at the first sign of swelling. Early treatment leads to



better outcomes. You should have been given information on self-care and told to notify your team of any signs of swelling or infection.

Surgery to remove the lymph nodes (or sentinel nodes) can result in injury to the nerves in that area. This damage can cause pain, numbness, tingling, decreased sensation or strength in the area or limb. Nerve injuries could be aggravated by scar tissue formation after receiving radiation therapy to the area. This type of pain is called nerve pain and is treated with different medications than other types of pain. If you are having nerve pain, it may be suggested that you meet with a pain specialist.

### Key Takeaways

- Radiation can increase your risk of lymphedema (swelling). Talk to your provider if you are having any new swelling. A Certified Lymphedema Therapist should be consulted at the first sign of swelling for best outcomes.
- Radiation and/or surgery can damage nerves, which can be worsened by scar formation and result in neuropathic pain (shooting or burning pain). You may need to see a pain specialist to manage neuropathic pain.

## Healthy Living After Cancer

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Survivors often wonder what steps they can take to live healthier after cancer. There is no supplement or specific food you can eat to assure good health, but there are things you can do to live healthier, prevent other diseases, and detect any subsequent cancers early.

In addition to medical problems and screening, cancer survivors also sometimes have issues with insurance, employment, relationships, sexual functioning, fertility, and emotional issues because of their treatment and we will discuss those in this care plan.

No matter what, it is important to have a plan for who will provide your cancer-focused follow up care (an oncologist, survivorship doctor or primary care doctor). You have taken the first step by developing a survivorship plan of care. If you would like to find a survivorship doctor to review your care plan you can contact cancer centers in your area to see if they have a survivor's clinic or search for a clinic on OncoLink's [survivorship clinic list](#).

### General Cancer Screening for Women after Breast Cancer

Cancer screening tests are designed to find cancer or pre-cancerous areas before there are any symptoms and, generally, when treatments are most successful. (Learn more about screening tests) Various organizations have developed guidelines for cancer screening for women. While these guidelines vary slightly between different organizations, they cover the same basic screening tests for breast, cervical and colorectal cancers, and are recommended to begin as early as the late teens.

In addition, during routine health exams (at any age) your healthcare provider may also evaluate for cancers of the skin, mouth and thyroid. Not all screening tests are right for everyone. Your personal and family cancer history, and/or the presence of a known genetic predisposition, can affect which tests are right for you, and at what age you begin them. Therefore, you should discuss these with your healthcare provider. Your care plan will also include a section on follow up care for your type of cancer, and these recommendations override the general screening recommendations for that particular type of cancer in the general population.

The American Cancer Society (ACS) recommends these screening guidelines for women:

#### Cervical Cancer Screening

All women should begin cervical cancer screening at age 25 using the following methods:

- Women between the ages of 25 and 65 should have:
  - Primary HPV testing every 5 years. This test is not yet available at many centers/practices.
  - If this test is not available, you should be screened with co-testing, which is a combination of an HPV and Pap test. This should be done every 5 years.
  - If HPV testing is not available, then a Pap test alone should be performed every three years.
- Women over age 65 who have had regular cervical screenings that were normal should not be screened for cervical cancer.
  - Women who have been diagnosed with cervical pre-cancer should continue to be screened until they meet one of the following criteria over the previous 10 years:
    - Two negative, consecutive HPV tests.
    - Or 2 negative, consecutive co-tests.
    - Or 3 negative, consecutive pap tests in the last 3-5 years.
- Women who have had their uterus and cervix removed in a hysterectomy and have no history of cervical cancer or pre-cancer should not be screened.
- Women who have had the HPV vaccine should still follow the screening recommendations for their age group.
- While the ACS does not recommend cervical cancer screening every year, women should still see their provider for a well-woman checkup.

Some women, because of their history, may need to have a different screening schedule for cervical cancer. Please see the ACS document, [Cervical Cancer Screening Guidelines](#) for more information.

### **Endometrial (Uterine) Cancer Screening**

The ACS recommends that at the time of menopause, all women should be informed about the risks and symptoms of endometrial cancer. Women should report any unexpected bleeding or spotting to their doctors. Some women, because of their history, may want to consider having a yearly endometrial biopsy. Please talk with your doctor about your past medical and gynecologic history to determine whether you are at increased risk for endometrial cancer.

*For More Information:*

Visit the [American Cancer Society](#) to learn more about general cancer screening recommendations.

### **Colon and Rectal Cancer Screening**

Most men and women over the age of 45-50 should undergo routine screening for colon and rectal cancer, up until age 75. The American Cancer Society suggests starting screening at age 45, whereas the United States Preventive Services Task Force suggests starting at age 50. Insurance may not cover screening before the age of 50 so you should talk with your provider and insurance company before screening. Testing may be appropriate for younger people with a high-risk personal or family health history.

Options for colon cancer screening can be divided into those that screen for both cancer and polyps, and those that just screen for cancer. Tests that screen for cancer and polyps include flexible sigmoidoscopy, colonoscopy, double-contrast barium enema, or CT colonography (virtual colonoscopy). Tests that screen mainly for cancer include stool testing for blood, or stool DNA testing. [Learn more about colorectal cancer screening options.](#)

The “preferred screening” recommended by the American College of Gastroenterologists is a colonoscopy every 10 years. The ACS recommends screening beginning at age 45 (unless you are considered “high risk,” see below), using one of the following testing schedules:

Tests that find polyps and cancer:

*(Preferred over those that find cancer alone. If any of these tests are positive, a colonoscopy should be*

done.)

- Flexible sigmoidoscopy every 5 years, or
- Colonoscopy every 10 years, or
- Double-contrast barium enema every 5 years, or
- CT colonography (virtual colonoscopy) every 5 years

Tests that primarily test for cancer:

- Yearly fecal occult blood test (FOBT)\*, or
- Yearly fecal immunochemical test (FIT) \*, or
- Stool DNA test (sDNA), interval uncertain\*

*\* The multiple stool take-home test should be used. One test done by the doctor in the office is not adequate for testing. A colonoscopy should be done if the test is positive.*

Talk with your doctor about your medical history, and what colorectal cancer screening test and schedule is best for you. For more information on colorectal cancer from the ACS, read [Colorectal Cancer: Early Detection](#).

Individuals at higher risk of colon cancer should have screening earlier and potentially more frequently. Individuals at higher risk of colon and rectal cancer include:

- Individuals with a family history of colon or rectal cancer in a relative who was diagnosed before the age of 60.
- Individuals with a history of polyps.
- Individuals with inflammatory bowel disease (Crohn's disease or ulcerative colitis).
- Individuals with a genetic predisposition to colon or rectal cancer, such as hereditary non-polyposis colon cancer (HNPCC) syndrome or familial adenomatous polyposis (FAP) syndrome.

For more detailed information regarding screening for individuals at higher risk for colon cancer, see the ACS [guidelines for screening for high-risk individuals](#).

## **Lung Cancer Screening**

The American Cancer Society does not recommend tests to check for lung cancer in people who are at average risk. However, they do have screening guidelines for those who are at high risk of lung cancer due to cigarette smoking. Screening might be right for you if you meet the following:

- 50 to 80 years of age and in fairly good health.
- Have at least a 20 pack-year smoking history AND are either still smoking or have quit smoking within the last 15 years (A pack-year is the number of cigarette packs smoked each day multiplied by the number of years a person has smoked. Someone who smoked a pack of cigarettes per day for 20 years has a 20 pack-year smoking history, as does someone who smoked 2 packs a day for 10 years.)

Screening is done with a low-dose CT scan (LDCT) of the chest. If you fit the list above, you and your provider should talk about whether to have screening.

## **Sun Exposure and Skin Cancer Risk**

Skin cancer is the most commonly diagnosed type of cancer, and rates are on the rise. However, this is one cancer that in most cases can be prevented or detected early. While you may hear that you need the sun to make vitamin D, in reality you only need a few minutes a day to do this. Exposure to ultraviolet (UV) rays, either by natural sunlight or tanning beds, can lead to skin cancer. In addition, UV rays lead to other forms of skin damage, including wrinkles, loss of skin elasticity, dark patches (sometimes called age spots or liver spots), and pre-cancerous skin changes (such as dry, scaly, rough patches). Although dark-skinned people are less likely to develop skin cancer, they can and do develop skin cancers, most often in areas that are not exposed to the sun (on the soles of the feet, under nails, and genitals).

You can do a lot to protect yourself from damaging UV rays and to detect skin cancer early. Start by practicing [sun safety](#), including using a broad-spectrum sunscreen (which protects against UVA & UVB rays) every day, avoiding peak sun times (10 am-4 pm when the rays are strongest) and wearing protective clothing such as hats, sunglasses and long-sleeved shirts.

Examine your skin regularly so you become familiar with any moles or birthmarks. If a mole has changed in any way, you should have a healthcare provider examine the area. This includes a change in size, shape, or color, the development of scaliness, bleeding, oozing, itchiness, or pain, or if you develop a sore that will not heal. If you have a lot of moles, it may be helpful to make note of moles using photographs or a “mole map”. The American Academy of Dermatology has a [helpful guide to performing a skin exam](#).

Learn more about the types of skin cancer on [OncoLink](#) and the [Skin Cancer Foundation](#).

## Healthy Lifestyle

For some cancer survivors, the experience is the impetus to making healthy lifestyle changes. It may seem insignificant, but these changes have been shown to reduce the risk of the cancer coming back or a new cancer developing. Below are some tips on adopting a healthier lifestyle.

- Do not use tobacco in any form. If you do, learn more on [OncoLink](#) and talk to your healthcare provider about taking steps to quit.
- Maintain a healthy weight. Many studies have found that excess weight plays an important role in cancer development and recurrence. While maintaining a healthy weight is important in cancer prevention, it cannot easily be separated from the importance of physical activity and eating a healthy diet. Strive to incorporate all three pieces of the puzzle: healthy weight, balanced diet, and regular exercise.
  - Talk to your healthcare team about what a healthy weight is for you, and take steps to reach and maintain that weight.
  - Experts recommend at least 30 minutes of moderate to vigorous activity per day, 5 days a week.
  - Eat healthy, including plenty of fruits and vegetables daily. Strive to have 2/3 of your plate be vegetables, fruits, whole grains, and beans, while 1/3 or less should be an animal product. Choose fish and chicken and limit red meat and processed meats.
  - Learn more about recommendations for diet, activity, and weight in the [AICR’s Guidelines for Survivors](#) and the [ACS Eat Healthy and Get Active](#) information on their website.
  - Learn more about the benefits of physical activity from [Macmillan Cancer Support](#).
- Limit how much alcohol you drink (if you drink at all).
- Have regular check-ups by a healthcare professional.
- Keep up-to-date on general health screening tests, including cholesterol, blood pressure, and glucose (blood sugar) levels.
  - Learn about healthy screening tests for [women](#) and [men](#) from the US Department of Health and Human Services.
- Get an annual influenza vaccine (flu shot).
- Get vaccinated with the pneumococcal vaccine, which prevents a type of pneumonia, and re-vaccinated as determined by your healthcare team. Learn more about [adult vaccinations from the CDC](#).
- Don’t forget dental and eye health!
  - The American Optometric Association recommends adults have their eyes examined every 2 years until age 60, then annually. People who wear glasses or corrective lenses or are at “high risk” for eye problems (i.e. diabetics, family history of eye disease) should be seen more frequently.
  - The American Dental Association recommends adults see their dentist at least once a year.

## Genetic Risk

Cancer is a condition where certain cells in the body are no longer growing and dividing normally. Genes are the instruction manuals contained in all of our cells. Cells receive many instructions from genes about when to grow and divide, and when to stop growing. If certain genes are not working properly (they have a mutation) then cells may not get the proper instructions about when to grow and divide and, as a result, cancer can develop.

In families with hereditary forms of cancer risk, a mutation is present in a single, very important gene, and is present at birth in all cells in the body. A child may inherit this gene mutation from a parent. Inheriting a mutation in a gene that plays a very important role in controlling normal cell growth substantially increases cancer risk. However, these cancer risk genes in no way guarantee that cancer will develop; inheriting a mutation in a cancer risk gene means only that your risk is higher than someone who does not carry such a mutation in their cells.

The American Society of Clinical Oncology suggests that you consider genetic testing if your personal or family history is suggestive of a genetic mutation, including:

- Cancer diagnosed at an unusually young age.
- Several types of cancer in the same person.
- Cancer in both organs in a set of paired organs, for example, both breasts or kidneys.
- Several close blood relatives with the same type of cancer (mother, sisters, daughter).
- Unusual cases of a specific cancer (for instance, breast cancer in a male).
- Presence of birth defects related to an inherited cancer syndrome (which can include skin growths or skeletal abnormalities).
- Being a member of a racial or ethnic group with a known higher risk of a hereditary cancer syndrome.

Not every family that has multiple cancer cases is found to have a genetic mutation. If you are concerned that your family may have such a mutation, you should consult with a genetic counselor. These trained professionals will review your detailed family history, discuss the risks, benefits, and limitations of genetic testing and help you decide what is right for you. If you do undergo genetic testing, the genetic counselor will help you understand how the results affect you and your family. They will also help you outline a plan for cancer screening that is tailored to your level of risk.

### Key Takeaways

- If you are concerned that your family may have such a mutation, you should consult with a genetic counselor.

## Fatigue

Fatigue is the most common side effect of cancer treatment. What many people do not know is that this feeling of overwhelming physical, mental and emotional exhaustion can last for months to years after therapy ends. Soon after treatment is complete, friends, family and co-workers often expect you to be back to doing the things you did before treatment, with the same energy level. Many survivors have significant fatigue for months or years after completing therapy, which can be extremely frustrating for the survivor and those around them. It is important to remember that fatigue can be caused by many things and, particularly if fatigue is worsening or new, it should be discussed with your healthcare team to rule out treatable causes.

Research has shown that exercise is the best way to improve fatigue related to cancer treatment. Start where you can – maybe that means a short walk around the block. Add a little more each day. Find a partner to walk with you (or do whatever activity you choose) and encourage you to stick with it. If you are up for more intensive exercise, be sure to talk with your oncology team to be sure you have no restrictions on what you can do.

Most importantly, you should understand that it is normal for fatigue to take time to resolve. You will need

to give your body time to slowly return to your former energy levels. The time it takes to get over this fatigue varies greatly depending on the treatment received, the type of cancer, how fatigue affected you during treatment, and how well you can balance the demands on your time. Use some of the tools you may have used during treatment – delegate, prioritize, make lists and group errands to cut down on trips to the store, etc.

Think of your energy as a bowl of candy. You start the morning with a full bowl, and every task takes one or two candies. You will need to continue to balance and prioritize your time and energy. Save a few candies for when you have something special to do in the evening. You will find that your bowl of candy will continue to get bigger every day. Using this metaphor will help you mentally manage your time and energy.

## Life After Cancer

While many patients are told about the long-term health effects of treatment before starting, they often don't recall or didn't concern themselves with them at that time. This is understandable. When you're presented with treatment options to save your life, thinking about what could happen ten or twenty years down the road isn't as much of a priority.

So, what to do now? You should learn what your risks are based on the treatment you received, learn what you can do to reduce these risks, if possible, and learn what to watch for. You have taken the first step by developing a survivorship care plan. Some survivors may also benefit from a visit to a survivorship clinic. These clinics review your treatment history and develop recommendations for you and your primary care team based on your risks. Contact cancer centers in your area to see if they have a survivor's clinic or search for a clinic on [OncoLink's survivorship clinic list](#) (though this list is not exhaustive).

After active treatment is complete, you will move into follow-up mode. This usually means you will see your oncology team less often. For many, this can be a very scary time. The weekly or monthly visits to the oncologist are reassuring. Someone is checking on things and giving you the thumbs up. Survivors are often surprised by their emotions at this time. You may anticipate jumping for joy and throwing a party. Instead, you may find yourself crying in the parking lot after your last treatment, feeling vulnerable in unexpected ways.

You may find it worrisome that you are no longer getting active treatment. You may miss the much-needed daily or weekly support you got from the oncology team. You may experience fear, sadness, anger, isolation, and grief. This is normal! You may also feel a sense of relief, gratitude, and be proud of yourself for getting through treatment – as you should!

The end of therapy is a time when friends and family may say, "Congratulations" and "You must be glad to be done." But you may be feeling uncertain about this milestone. Friends, family, and even the oncology team can be surprised by the complicated emotions you are experiencing. They may not realize that these emotions are common and even expected, which may make you feel even more isolated. You aren't alone. These are common reactions and the information in your care plan will help you transition to survivorship.

For starters, be assured that your oncology team is always there if you have any concerns. Plans for follow-up care have been developed to follow each person in the best way. This plan varies for every type of cancer and may involve periodic blood work, radiology scans and tests, and physical exams. You may only see the oncology team once or twice a year, but they are always a phone call away.

### Coping with your emotions after cancer

Any time of transition in your life can be stressful. Give yourself time to adjust to this new place. You may hear from others, "it must be nice to be getting back to normal." But as any cancer survivor will tell you, things have changed. So has your definition of "normal". Many survivors say they look at life differently. They don't take things for granted and don't sweat the small stuff.

A cancer diagnosis changes you as a person, something people around you may not fully understand. It may be helpful to join a group of survivors, either formally (in a support group) or informally (gather with



few folks you have met along the way). Email and the Internet have created wonderful support for all sorts of concerns, and survivorship is no different. There are also professional resources available to help.

- [CancerCare](#) provides online and telephone support groups.
- The [Cancer Support Community](#) has a number of locations across the US that provide education, support, and networking to cancer survivors and their families. Their [Helpline](#) can also help you find other survivorship resources.
- Many cancer centers and cancer service organizations offer support groups for you to talk about concerns during and after treatment. A “buddy” program can match you with someone who’s been in your shoes and can be a listening ear and support person – or you can become a buddy to someone else. No one understands this time better than someone who has been there, and this support can be very valuable. Peer support/[Buddy programs](#) are offered through many organizations including [Imerman Angels](#), [Cancer Hope Network](#), Living Beyond Breast Cancer, and the Leukemia and Lymphoma Society.

For many, a cancer diagnosis and treatment is a traumatic experience. Recovering from this trauma can be complicated by the late side effects of treatment. These side effects can impact your quality of life long after you have finished your cancer treatment. Some survivors experience symptoms of post-traumatic stress disorder. This can include sleep problems, nightmares, flashbacks, avoiding places associated with the experience (like your treatment center), feeling hopeless, anger, and guilt (including survivor's guilt), loss of interest in things you usually enjoy, and substance use.

It is important to find ways to cope with the trauma of cancer and your experiences. If you are having symptoms of post-traumatic stress, ask your care team for a referral for [counseling](#). Your oncology social worker can help navigate your insurance and find an experienced provider who can give you support and therapy. Your team can also refer you for psychiatry support if medication treatment may be helpful in treating your post-traumatic symptoms.

However, out of trauma, comes the possibility of growth. You can use this experience to change and grow psychologically and emotionally. Even out of the most challenging experiences in our lives, there is room for growth, improvement, and change.

You may ask yourself, “how has cancer changed me?” Many patients have said, “cancer is the best thing that ever happened to me.” Cancer taught them to live. To appreciate the simple things in life. To love. To give back. To be close to others and show compassion. After treatment, you may try new things, decide it’s time to take that trip you have always been wanting to do, join a spiritual community, or even find a way to “give back” through volunteer work, advocacy, and fundraising for a cancer service organization. All of these activities help you grow after cancer.

Some cancer patients have depression and anxiety during and after treatment. Many patients express “scanxiety” when having their routine scans for follow-up. They worry about what the scans may show - “has my cancer come back?” This is normal after going through such an experience. It’s important to talk to your team if you are having these feelings. They do usually improve with time and with your improved abilities to cope with worry and fear. However, sometimes they don’t go away or even get worse. This is a time for concern. Signs of persistent depression and anxiety include trouble sleeping (insomnia) or sleeping too much (hypersomnia), hopelessness, inability or unwillingness to participate in normal activities and even thoughts of self-harm or suicide. If you are having these symptoms, talk to your care team immediately.

### **Coping with practical concerns after treatment**

It is essential to maintain your health insurance after you have completed treatment so you can get your follow-up care. Because your health insurance is often related to your job, you may be wondering about returning to work or starting a new position. This can also help to re-establish some normalcy in your life after treatment. However, returning to work can be a challenge. For some, disability is the best option. Talk with your care team about your desires for work after treatment. There are also some great resources for navigating work, disability, and insurance.



- Learn about your rights and your employer's responsibilities under the law. You may want to talk with human resources professionals at your job about things like returning to work, FMLA, and reasonable accommodations.
- [OncoLink's section](#) on legal, insurance, employment, and financial concerns provides great information about these issues.
- [Cancer and Careers](#) is a resource for all things work-related, from time of diagnosis well into survivorship.
- The [National Coalition for Cancer Survivorship](#) and the [American Cancer Society](#) websites have financial and insurance information for survivors.
- The [Cancer Legal Resource Center](#) and [Triage Cancer](#) provide information on cancer-related legal issues, including insurance coverage, employment and time off, and healthcare and government benefits.

## Relationships after cancer

Cancer can have a profound impact on your relationships. This can include our friendships (new and old), our family, our co-workers, or even a dating/intimate relationship. As cancer survivors, you may ask yourself: when, what and how do I tell someone that I am a cancer survivor? Or perhaps, do I even need to tell them?

Telling someone about your cancer history can be particularly challenging if you are thinking about dating and new intimate relationships after cancer. You may have physical scars from your cancer treatment. You may also experience changes to your sexual health and function as a result of your treatment. A new partner may bring up questions about your ability to get pregnant or father a child. This is a lot for a cancer survivor to navigate.

It's important that you are comfortable "in your own skin." Think about what you want to share with someone new in your life. Perhaps, give them small pieces of information to start to gauge their comfort level. If they ask questions about your scars, be prepared with what you want to say about them. Practice your talk with a trusted friend. Therapy after treatment can also help you strategize how to talk with a new partner about your cancer history and its long-term impact on your life.

## Sexual health and fertility

How cancer affects your sexuality is different for every survivor. Some find the support they need through their healthcare team, their partner, friends, or fellow survivors. Some cancer advocacy groups host discussion boards where you can "talk" about concerns with someone who has been there. The [American Cancer Society](#) and [LIVESTRONG](#) both offer sexuality information for men and women. Couples and/or sex therapists are extremely helpful for couples who are struggling with intimacy after cancer. Ask your team or social worker for referrals to therapists who are experienced in sexual health issues after an illness.

Issues related to sexuality or fertility can be emotionally draining and can interfere with personal relationships at a time when you need them most. OncoLink's section on [fertility & sexuality](#) may be helpful. Organizations such as the [Oncofertility Consortium](#), [LIVESTRONG](#), and [Resolve](#) can help with fertility questions and issues. [Us Too](#) and the [American Cancer Society](#) both provide fertility and sexuality resources.

All of this can be a bit overwhelming, but the fact that there are over 17 million cancer survivors in the United States today is a testament to the fact that you can do this! Take it one day at a time and seek the support you need to live and love your "new normal" life.

## Living with Metastatic Cancer

Metastatic cancer is when cancer spreads to other parts of the body. Metastatic cancer means something different to each person that hears those words. What this means for prognosis is no different. Advances in therapies allow some cancers to become more like a chronic illness, with people surviving for many years on and off therapy. For others, time may be much more limited. Either way, you can still aim for managing

your symptoms and making your quality of life a priority.

Typically, patients have many questions about what to do next in the face of metastatic disease including:

- How do I cope with metastatic disease?
- How will my family take the news?
- Can I continue to work, or should I look into my options for disability?
- What are my treatment options?
- Do I want more treatment?
- If I chose not to have more treatment, what other options are available for me?

You may experience a wide range of emotions including fear, shock, surprise, anger, loss, sadness, and worry. You may feel like you are losing control and be overwhelmed by the notion of “what’s next.” This is all normal. These feelings usually improve over time as we learn how to cope and tap into our own abilities to be resilient in times of stress. However, sometimes they don’t go away or even get worse. This is a time for concern. Signs of persistent depression and anxiety include trouble sleeping (insomnia) or sleeping too much (hypersomnia), hopelessness, inability or unwillingness to participate in normal activities, and even thoughts of self-harm or suicide. If you are having these symptoms, talk to your care team immediately.

Don't hesitate to ask for help - social workers, therapists, support groups (in person or online) can provide support and listen to your concerns. They can also refer you to additional resources that may help guide you through this time. Family, friends, and clergy or spiritual guidance can be great sources of support during cancer treatment.

If you have been through cancer treatment before, remember you know much more now than you did when you were first diagnosed. Use your knowledge to guide your treatment decisions and help you put into place the support you need to get through this next part of your cancer journey.

If you are newly diagnosed with cancer that has spread, call on your best support people to help you research treatment options, weigh pros and cons and make decisions. Bring your support person(s) to your appointments to take notes, ask questions and help you remember what was discussed when you get home. If they can't come to appointments with you, can they call in, or is a telemedicine appointment with your team available?

Likely you were hopeful for a cure or remission for your cancer. You can still be hopeful for control of your disease and symptoms and good quality of life. Focus on achievable daily goals, like going to a child's soccer game or having lunch with a friend. This can help you appreciate the "little" treats in life and keep you focused on the good things.

Some survivors like to set a long-term goal or milestone, such as seeing the birth of a grandchild or going to a special event. Be realistic in your goals, accept that you won't always be up for the task and may need to adjust your goals for the day based on how you feel. Tell your healthcare providers, your family, and friends about the things that you are hopeful for. Don't be afraid to ask for help when needed.

Hearing the words, “you have metastatic cancer”, can be a punch to the gut. But the cancer hasn’t “won.” You have lots to live for and with advances in palliative care, good symptom management can help you have a good quality of life. It’s ok to be realistic while enjoying life and time with the people you love.

Resources for More Information

[Understanding Advanced and Metastatic Cancer](#), American Cancer Society.

[Metastatic Cancer: When Cancer Spreads](#), NCI

# Tobacco

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## Tobacco Use and Quitting Smoking

Quitting tobacco is the single most important step you can take to extend the length and quality of your life. And the benefits happen almost immediately!

- Just 20 minutes after quitting, your heart rate and blood pressure drop.
- In just a few weeks, your lung function increases.
- One year after quitting, your risk of heart disease is ½ that of a smoker.
- Second-hand smoke puts our loved ones at an increased risk of cancer, and lung and heart disease. Quitting protects your family.
- Tobacco use is expensive. Quitting will put money back in your pocket right away.

If you are a cancer survivor, quitting is also important. Using tobacco during and after cancer treatment can make it harder for you to get through treatment. Tobacco can also affect how well your treatments work, how wounds heal after surgery, and can increase the side effects experienced during and after treatment.

But quitting tobacco is tough. Tobacco use isn't just a habit, it is an addiction. An addiction to nicotine happens with the regular use of products that contain nicotine. This causes you to have a physical and behavioral need for it—a craving. On top of that, as you use more nicotine, your brain develops a tolerance to it. This means that over time, you need more and more nicotine to satisfy your cravings. This is what makes quitting so hard.

### **How do I quit?**

- Decide to quit and commit to that decision. You have to want to quit.
- Write down all the reasons you want to quit and put it in a place where you can easily be reminded of why you made the decision to stop using tobacco.
- Identify what makes you want to use tobacco. When do you normally smoke—in the car on the way to work? During breaks at work? Before something that makes you anxious, like giving a presentation or going to a follow-up visit? Or, socially at a bar or after a meal? Successful quitting takes changing your routines. This is a lifestyle change. Maybe take public transportation to work, take a walk with a co-worker, or meditate before that presentation or appointment. Trying new things can help you avoid the situations where you are used to using tobacco.
- This doesn't mean you have to quit right this minute. Experts suggest setting a quit date within the next two weeks and sticking with it. Taking time to get ready can help you be more successful.
- Let your family, friends, co-workers, and other important people in your life know that you are quitting and what your quit date is.
- Think about ways you can engage your support people in helping you quit. Help them understand that you may be more moody, irritable, and not acting like yourself for a while.
- Another friend who has quit or a helpline can be an excellent resource in those moments when you are having a hard time.
- Talk to your healthcare provider. Quitting can cause you to have physical and psychological symptoms of nicotine withdrawal. These include irritability, sadness, depressed mood, headaches, cravings, and difficulty concentrating. There are medications available to help manage some of these symptoms.
- If you smoke more than 10 cigarettes per day, you should use nicotine replacement therapy (NRT) as part of your quitting plan. NRT works by partially replacing the nicotine you were getting through tobacco. This reduces withdrawal symptoms and cravings. There are also other medications that can help you quit. Your healthcare provider can help you choose which is best for you.
- Contact your health insurance company to ask if tobacco cessation programs and medications are covered by your plan. Learn more about smoking cessation aids on [OncoLink](#).
- Throw it all away. On quit day, be sure you have gotten rid of all tobacco products—even those in your secret hiding places. Also get rid of things that go along with smoking like lighters, matches, and ashtrays.
- Make sure you have gum, mints, or candy on hand to keep your mouth occupied. Doodle, draw, write

or think of ways to keep your hands busy too.

- Quitlines, online chat rooms, texting, and mobile phone apps can help you connect with others who are trying to quit, as well as give you support “on demand.” It is important to know you are not in this alone. Ask others who have quit for their “tips and tricks” for quitting.
- Many employers are incorporating incentive programs for their employees to quit—including lower health insurance premiums. Ask your manager or human resources department if these programs are available at your job.
- Remember that you may not be successful with quitting on your first try. Or even your second or third. On average, it takes seven attempts to quit for good. If you happen to smoke or use another product again, get back on the quitting wagon right away. This is called a slip. It can be helpful to think about what led up to you smoking again—was it stress at work? An upcoming medical appointment? An argument with a friend? Boredom? How can you prevent a slip from happening again? Remember, quitting is hard. Celebrate every smoke-free day.

## Resources

[The American Cancer Society](#): (800-ACS-2345) offers free education and resources for quitting tobacco, including cigarettes, vaping, and smokeless tobacco.

[Centers for Disease Control](#), offers a toll-free telephone number, 1-800-QUIT-NOW (1-800-784-8669), which serves as a single point of access to quit lines available in all 50 states. Also offers free quit coaching, quit planning materials, the quitSTART app, a free texting program, and referrals for local support and resources. Offers information and support in Spanish, Mandarin, Cantonese, Korean and Vietnamese.

[Smokefree.gov](#): provides free, accurate, evidence-based information and professional assistance to help support the immediate and long-term needs of people trying to quit smoking.

[Tobacco Free Kids](#): one of the nation's largest non-governmental initiatives, with the goal of protecting children from tobacco addiction and exposure to secondhand smoke. They offer talking points and support for parents

[Freedom from Smoking](#): This online resource for adults is an adaptation of the American Lung Association's gold standard, group clinic that has helped thousands of smokers to quit for good.



OncoLink is designed for educational purposes only and is not engaged in rendering medical advice or professional services. The information provided through OncoLink should not be used for diagnosing or treating a health problem or a disease. It is not a substitute for professional care. If you have or suspect you may have a health problem or have questions or concerns about the medication that you have been prescribed, you should consult your health care provider.