

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

- Lumpectomy
- Sentinel Node Biopsy
- Cyclophosphamide (Cytoxan®, Neosar®)
- Doxorubicin (Adriamycin®, Rubex®)
- Tamoxifen (Nolvadex®)
- Radiation treatment for breast cancer after lumpectomy

## Information from your oncology office

## 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.

## What's In Your Care Plan

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## Follow Up Care For Breast Cancer

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

Survivors who have had breast conserving therapy (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 should examine the chest wall for swelling or rash, and report any changes to their oncologist. Some oncologists will recommend mammograms for women who have reconstructed breast(s).

Survivors should be seen by their oncologist every 3 to 6 months for the first 3 years and then every 6-12 months for the next 2 years, and annually after 5 years. Women who are taking tamoxifen and still have an intact uterus should be seen annually by a gynecologist and be sure to report any vaginal bleeding to their physician immediately, as this can be a sign of uterine cancer. Women taking an aromatase inhibitor, which results in a decrease in estrogen levels and can lead to loss of bone strength, should have their bone health evaluated by a DEXA scan at baseline and then periodically thereafter.

Routine 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.

Finally, research has demonstrated that leading an active lifestyle and maintaining a healthy weight, with a body mass index (BMI) of 20-25, may result in better breast cancer outcomes. Weight bearing exercise, 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!

Recommendations for patients with breast cancer include:

- Mammogram annually for those who have had a single mastectomy (the first mammogram should be six months after therapy for survivors who underwent lumpectomy and radiation therapy).
- Perform monthly self-breast exams and / or examination of the chest wall and scar line. Report any changes, lumps, swelling or skin rashes to your physician.
- Women with an intact uterus on tamoxifen should see a gynecologist annually and notify their physician of any vaginal bleeding.
- Women taking aromatase inhibitors whose menstrual cycles have stopped should have a DEXA scan as a baseline, then periodically.
- Consider referral to genetic counseling if family or personal history includes early age at diagnosis of breast cancer (<50), triple negative disease, multiple primary cancers, or a family history of breast or ovarian cancer.
- Evidence has shown that leading an active lifestyle and maintaining a healthy weight (body mass index of 20-25), may lead to improved breast cancer outcomes.
- Any new, unusual and/or persistent symptoms should be brought to the attention of your care team.

## Risks Related to Medications

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### Risk of Developing Cataracts

The risk of developing cataracts is linked to busulfan, corticosteroids (dexamethasone, prednisone), tamoxifen, anastrozole and radiation therapy involving the eye (including total body irradiation). Survivors should report any symptoms of cataracts and have an eye exam performed by an ophthalmologist every few years. Symptoms of cataracts include: blurry vision, light sensitivity, poor night vision, double vision in

one eye, seeing halos around objects, needing brighter light to read or fading or yellowing of colors.

### Key Takeaways

- Have an eye exam by an ophthalmologist every 1-2 years
- See your doctor if you experience any cataract symptoms
  - Blurry vision
  - Light sensitivity
  - Poor night vision
  - Double vision in one eye
  - Seeing halos around objects
  - Needing brighter light to read
  - Fading or yellowing of colors

## Risk of Bladder or Urinary Tract Toxicities

The risk for bladder and urinary tract toxicities is highest for survivors who received cyclophosphamide (doses > 3g/m<sup>2</sup>), ifosfamide and/or radiation to the abdomen. Late effects to the urinary tract can include hemorrhagic cystitis, a condition characterized by bleeding from the bladder lining and bladder scarring leading to a decrease in the bladder capacity. Symptoms of hemorrhagic cystitis include urinary frequency and urgency, blood in the urine and pain. Bladder scarring can present as difficulty urinating, frequency or urgency. Survivors at risk should report these symptoms to their healthcare provider right away. Survivors should understand that alcohol use and smoking can contribute to bladder dysfunction, so these should be avoided.

### Key Takeaways

- Avoid alcohol
- Avoid smoking
- Report the following symptoms to your healthcare provider
  - Pain when urinating
  - Urinary hesitancy (difficulty starting the stream)
  - Urinating frequently
    - Urinating more than 5 times per day
    - Getting up in the middle of the night to urinate
  - Blood in your urine

## Risk of Developing Bladder Cancer

In rare cases, cyclophosphamide, ifosfamide and streptozocin can contribute to the development of bladder cancer. This risk is increased for those who also received radiation therapy to the abdomen. Symptoms of bladder cancer include blood in the urine, urinary frequency and urgency, urinating at night and incontinence and should be reported to the healthcare provider. Survivors should be counseled that alcohol use and smoking can contribute to bladder cancer, so these should be avoided.

### Key Takeaways

- Avoid alcohol
- Avoid smoking
- Report the following symptoms to your healthcare provider
  - Pain when urinating
  - Urinary hesitancy – starting and stopping while urinating
  - Urinating frequently
    - Urinating more than 5 times per day
    - Getting up in the middle of the night to urinate
  - Blood in your urine

## Risk for Cardiac (Heart) Problems Related to Anthracycline Chemotherapies

The group of chemotherapy agents called anthracyclines are known to cause specific cardiac toxicities, including cardiomyopathy (weakening of the heart muscle), arrhythmias (rhythm abnormalities) and left ventricle dysfunction (causing heart failure). The risk of developing one of these problems is tied to the cumulative (lifetime) dose a person has received, but even low doses can lead to abnormalities. Toxicity can develop anywhere from shortly after completing chemotherapy to decades later (called delayed). For example, it is known that cumulative doses of doxorubicin greater than 550mg/m<sup>2</sup> can lead to an increased risk of cardiac toxicity, but doses as low as 250mg/m<sup>2</sup> can result in subclinical cardiac changes. Subclinical changes can be detected on tests such as ECG, echocardiogram and/or MUGA scan, and often, these changes do not cause symptoms for the survivor. The doses of the various anthracycline agents are not equivalent, so you should discuss the dose you received and your risk with your provider.

This risk is higher for those who also receive other cancer therapies with cardiac side effects or radiation therapy that includes the heart. In addition, pre-existing cardiac problems, such as high blood pressure or CVD (cardiovascular disease) increases the risk of cardiac side effects. Survivors should maintain healthy lifestyles as smoking, drug use, obesity, sedentary lifestyle and poor dietary choices can increase the risk of cardiac disease.

Cardiac toxicities can cause symptoms such as shortness of breath (with or without exertion), orthopnea (difficulty breathing when lying down), chest pain, palpitations, exercise intolerance, dizziness/lightheadedness or edema (swelling of the extremities). In younger survivors (under age 25), cardiac symptoms may present as abdominal symptoms such as nausea and vomiting.

Annual history and physical by a healthcare provider should include a cardiac exam and review of possible symptoms. Survivors who received anthracyclines (any dose) should have had their left ventricular function evaluated at baseline with an echocardiogram, as studies have found many people with abnormalities did not exhibit symptoms. Experts suggest repeat evaluation of ventricular function between 6 and 12 months after the conclusion of anthracycline therapy for those survivors considered at high risk for cardiac problems. New or worsening symptoms should be reported to your care provider and may prompt further investigation with cardiac blood work and/or echocardiogram.

### Key Takeaways

- Maintain healthy lifestyle:
  - Avoid smoking.
  - Avoid drug use.
  - Maintain a healthy weight.

- Exercise regularly eat a well-balanced diet.
- Have an annual physical exam that includes a cardiac exam
  - Experts suggest echocardiogram between 6 and 12 months after therapy for those survivors considered at high risk for cardiac problems.
  - New or worsening symptoms should prompt further investigation with cardiac blood work and/or echocardiogram.
  - Monitor and manage blood pressure and cholesterol levels.
- Report the following symptoms to your healthcare provider:
  - Shortness of breath (with or without exertion).
  - Difficulty breathing when lying down.
  - Chest pain / heartburn.
  - Palpitations.
  - Dizziness/lightheadedness.
  - Swelling of the arms or legs.
- If you received chemotherapy under age 25, report symptoms of nausea and vomiting.

## Risk of Developing Osteoporosis

Osteoporosis and osteopenia (the precursor to osteoporosis) are decreases in bone density, which increases the risk of fracture of the affected bones. Long term use of corticosteroids (dexamethasone or prednisone, > 5mg per day for more than 2 months), receiving chemotherapy medications or radiation to weight bearing bones (spine, hips, legs) all increase the risk of developing osteoporosis.

Women who develop premature menopause, have their ovaries removed before menopause or those who take aromatase inhibitors (anastrozole, letrozole and exemestane) are at increased risk for osteoporosis. Men who receive hormone therapy for prostate cancer or undergo orchiectomy are at greater risk. In addition, patients who have undergone gastrectomy (removal of the stomach) are at increased risk to develop osteoporosis.

As for lifestyle risks, smokers, people who consume excessive alcohol and those who do not participate in weight bearing exercise have an increased risk of developing osteoporosis. Therefore, it is very important that survivors not drink alcohol or smoke. In addition, survivors should engage in weight-bearing exercise such as walking, weight lifting, riding a stationary bicycle, jogging, dancing, and any exercise where the legs are supporting the body's weight. These efforts, combined with increasing calcium and vitamin D in your diet and taking calcium and vitamin D supplements, will greatly help to reduce your risk of developing osteoporosis.

Survivors at risk should have adequate intake of calcium (1200-1500mg total per day, taken in divided doses) and vitamin D (400-800 international units per day if under age 50, and 800-1000 international units per day if over age 50). Calcium supplements are an easy way to get the recommended daily amount and come in 2 forms: calcium carbonate and calcium citrate. The body does have some trouble absorbing large amounts of calcium, so supplements should be split into 2 or more doses per day. Calcium carbonate requires stomach acid to be absorbed by the body, therefore people that take acid reducers (such as Zantac, Tagamet) and/or proton pump inhibitors (such as Prilosec, Prevacid, etc) should use calcium citrate. If you have trouble tolerating your calcium supplement, talk to your doctor or nurse; there may be another formulation you can tolerate more easily. It is important to take Vitamin D with the calcium supplements because it helps your body to absorb calcium better. Survivors should talk to their healthcare provider about screening with DEXA scan (a test used to assess bone density) and options for treatment, if necessary.

### Key Takeaways

- Avoid smoking and excessive alcohol intake.
- Perform weight bearing exercise 2-3 times per week.
- Calcium intake of 1200-1500mg per day plus Vitamin D 400-800iu or 800-1000iu per day (either in dietary intake or supplements).
- Consider screening with DEXA scan.

## Risk of Liver Toxicity

Hepatic dysfunction is abnormal functioning of the liver. This can range from having abnormal results on a blood test with no symptoms to cirrhosis or liver failure. The majority of complications tend to occur during or soon after therapy and patients who receive methotrexate, mercaptopurine, thioguanine, BCNU (carmustine), plicamycin and tamoxifen are at highest risk of developing liver problems. Toxicities may resolve over time, but in some cases, can result in chronic liver problems.

### Key Takeaways

- Avoid alcohol.
- Obtain blood work annually to check liver function while on therapy.

## Skin Toxicities

Some chemotherapy agents will cause the skin to darken or lighten in spots or cause the nails to change color or fall off. While this typically happens while on therapy, these effects can become chronic. Good hygiene and skin care, including washing with a mild soap and water, hydrating lotions for dry or scaly skin, and protecting any open skin wounds can all aid in recovery from these toxicities.

### Key Takeaways

- Practice good hygiene and skin care using mild soaps and hydrating lotions.
- Protect open skin wounds and report any signs of infection (redness, tenderness, drainage) to your healthcare team.

## Understanding Chemo-brain

Many survivors who have previously received or are currently undergoing chemotherapy report experiencing cognitive changes, often referred to as "chemo-brain." These changes include difficulty with short term memory, multi-tasking, new learning, reading comprehension, working with numbers and a decrease in concentration ability. For many years this was attributed, by physicians and researchers, to depression or anxiety over the diagnosis and treatment of cancer. More recently, researchers have begun to study and document what survivors have been saying all along; cognitive changes after chemotherapy are real. Although we are not yet able to pinpoint whether only certain chemotherapies are responsible, it seems certain that the effects are cumulative. That is, those who receive more chemotherapy tend to experience greater deficits. Studies have found that cognitive ability can improve over time in some survivors, but deficits are still present in many long term survivors, years after treatment.



Some medications are being studied as potential treatments for cognitive changes, but there is not yet enough data to support their use. Some of the agents being studied include: methylphenidate (Ritalin), modafinil (a medication approved to treat narcolepsy), various antidepressants, herbal therapies, such as ginkgo biloba, ginseng and certain amino acids. Cognitive rehabilitation programs are structured programs utilizing 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. Puzzles using numbers, like Sudoku, may help "exercise" your brain. Fatigue can enhance cognitive problems, so avoiding fatigue by getting enough sleep, incorporating exercise into your life and eating a healthy diet may be helpful.

It is important to remember that some very treatable problems can result in cognitive difficulties, such as thyroid dysfunction, depression and anxiety, so it is important to exclude or treat these diagnoses. 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 may be depressed or experiencing anxiety would benefit from consulting with a psychiatrist or psychologist experienced in working with cancer patients or survivors.

### Key Takeaways

- There is no standard treatment for chemo brain, but cognitive rehabilitation / brain games, avoiding becoming fatigued, a healthy diet, and some medications can be helpful.
- Use reminders, whether through lists, notes or smart phone alarms, 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

Resumption and preservation of fertility after cancer therapy is a very complex topic. It has not been very well studied, but is related to the doses and types of medications received, if radiation was also received, the age at time of treatment and, for women, the number of oocytes (eggs) present when therapy started. With all of these variables, there is no way to easily predict a survivor's reproductive health. In many studies, female survivors' reproductive status was evaluated by the resumption of menses after therapy, but this is in no way a guarantee of fertility, making it difficult to interpret these results for women when discussing risk for infertility.

Survivors who wish to become pregnant or evaluate their fertility should consider seeing a reproductive specialist who has experience working with cancer survivors. Testing may be performed to help evaluate fertility, including certain hormone levels and counting the number of developing follicles early in a woman's cycle (called an antral follicle count). [LIVESTRONG](#) maintains a list of specialists and offers financial assistance to cancer survivors. For survivors who have already completed therapy, The [OncoFertility Consortium](#) and The National Infertility Association's website, [Resolve](#), offers information on fertility treatments and testing, adoption, and deciding to not have children. This site also offers information on individual state laws about fertility coverage by insurers. Some experts suggest that women with a history of cancer and cancer treatment should be considered high risk for complications during pregnancy and should consider seeing a high risk obstetrician. This is particularly important if you received radiation to the abdominal area, had surgery involving female reproductive organs, or if you received chemotherapy that can cause heart damage.

Chemotherapy agents that are most strongly tied to infertility include: alkylating agents, cytarabine, vinca alkaloids, and bortezomib. Radiation fields that include the female pelvis or brain can also affect fertility. It



is not well understood how many of the newer agents will affect long term fertility. Women who do resume menstruation after cancer therapy should be aware that they could still start menopause earlier than expected, which may be a consideration when planning a family. To learn more about fertility related to cancer treatment, please see [OncoLink's section on sexuality and fertility](#) or [the OncoFertility Consortium](#).

Of equal importance is that cancer patients and survivors recognize that a gray zone exists after menstruation stops, when fertility may be possible. Even if a woman's periods stop during treatment, she may be able to get pregnant. For this reason, use of birth control during cancer treatment for any premenopausal patient is essential. Accidental pregnancy during cancer treatment can be difficult to cope with, as it may limit the treatments available.

### Key Takeaways

- Survivors wishing to become pregnant should consider consulting with a fertility specialist familiar with cancer survivors.
- Pregnant survivors should talk with their provider about whether or not they need to be followed by a high-risk obstetrician.
- Cancer patients should be aware that getting pregnant may be possible even after menstruation has stopped. Because treatments such as chemotherapy and radiation may be dangerous to an unborn baby, all patients who were actively menstruating before beginning cancer treatment should use birth control during cancer treatment, even if periods have stopped.

## Side Effects While taking Tamoxifen

Your OncoLife Care plan focuses on late effects of therapy, or those that can occur months to years after completing therapy. Current hormone therapy regimens last anywhere from 5 to 10 years, so we felt it was important to include some information about the acute side effects of these agents.

Tamoxifen commonly causes hot flashes and other symptoms of menopause. 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 and exercise regularly. For some women, certain antidepressant medications can provide relief of hot flashes.

The more serious, though low risk, complications of tamoxifen include endometrial cancer and blood clots. Women should promptly report any menstrual irregularities, vaginal bleeding, pelvic pressure/pain, or any vaginal discharge, as these may be symptoms of endometrial cancer. An endometrial biopsy should be done to test for cancer if any of these symptoms occur.

Blood clots are rare, but most often occur in the calf or lung. Signs of a blood clot in the leg may include any of the following: leg pain, warmth, swelling of one leg more than the other. Signs of a blood clot in the lung could include: fever, shortness of breath that comes on you very quickly, racing heart, chest pain (that tends to be worse when you take a deep breath). Any of these symptoms should be reported to your physician immediately.

### Key Takeaways

- You may experience hot flashes and other symptoms of menopause. Let your healthcare provider know if these symptoms become troublesome.
- There is a small risk of developing endometrial cancer. Be sure to report any irregular vaginal bleeding or pelvic pain/pressure promptly.

- There is a small risk of developing blood clots (typically in the leg or lung). Notify your healthcare provider immediately if you experience any leg pain, warmth, swelling of one leg, fever, shortness of breath that comes on you very quickly, racing heart, or chest pain.
- Discuss side effects with your oncology team, as many of these are manageable. Optimal therapy can last 5 years, so management of side effects is critical to helping you stay on therapy.

## Sexuality Concerns for Female Survivors

Women of any age may have sexuality concerns after cancer treatment. Do not hesitate to talk with your oncology team about these common concerns. Chemotherapy agents are associated with vaginal dryness, painful intercourse, reduced sexual desire and ability to achieve orgasm. Many of these issues are caused by the sudden onset of menopause, which can occur with cancer therapy. This sudden change in hormone levels leads to physical changes such as vaginal atrophy (thinning and inflammation of the vaginal walls), loss of tissue elasticity and decreased vaginal lubrication. In addition, women may experience hot flashes, mood swings, fatigue and irritability.

Decreased lubrication leading to painful intercourse is a common concern for survivors. This can often be [treated with vaginal lubricants](#) and moisturizers and/or estrogen therapy (taken orally or used in the vagina). Women who have had a hormone dependent cancer should discuss current research on using these therapies with their healthcare team. Surgery and/or radiation therapy can result in scarring that may cause discomfort during intercourse. Open communication about position changes and alternative methods of expressing affection with your partner can help when resuming sexual activity after treatment.

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 effect 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 sexuality issues is communication, both between partners and between survivors and their healthcare teams. 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

- Chemotherapy agents are associated with vaginal dryness, painful intercourse, reduced sexual desire and 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 all show benefit in relieving menopausal symptoms.
- Talk to your healthcare team about tips to manage these issues.
- Open communication with your healthcare team and partner are essential for regaining your sexuality and resolving issues. You may also consider talking with a therapist experienced in working with cancer survivors.

## Risk of Developing a Secondary Cancer

A secondary cancer is one that develops as a result of cancer treatment for another cancer. This is quite rare, but you should be aware of the risk. In most cases, secondary cancer related to chemotherapy is a blood cancer, though some medications have been linked to other cancer types.

Certain chemotherapy medications can cause damage to the blood cells in the bone marrow. In rare cases, this damage can cause leukemia or myelodysplasia (MDS) to develop years after therapy has been completed. Both diseases cause an abnormal production of poorly functioning blood cells, making it difficult for the body to fight infection, carry oxygen to the tissues and prevent bleeding. Because these conditions develop as a result of chemotherapy or radiation exposure, they are often more difficult to treat than typical leukemia or MDS. Leukemia and MDS caused by chemotherapy or radiation therapy typically occurs between 4-10 years after treatment, but can occur even later. One exception is those caused by etoposide (VP-16) or teniposide (two types of chemotherapy), which generally occur within 1-3 years after therapy.

Secondary lymphomas have also been seen in Hodgkin's disease survivors who received the MOPP (nitrogen mustard, vincristine, procarbazine, and prednisone) chemotherapy regimen. Bendamustine has been linked to secondary lung cancers.

### Key Takeaways

- There is a small risk of developing leukemia, myelodysplastic syndrome, lymphoma or other cancer years after your treatment is completed.
- Report the following symptoms to your healthcare provider promptly:
  - more tired or weaker than usual
  - shortness of breath
  - loss of appetite
  - weight loss
  - chills, fever, night sweats
  - painless swelling of a lymph node
  - easily bruising, nose bleeds, bleeding from the gums
- Consider having a complete blood count with differential checked annually by your healthcare provider if you received high risk therapies.

## What We Do Not Know

There are many medications of which we do not know the long term effects. Because of the combination of multiple drugs for most cancer treatments, it is sometimes 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 in reliable journals and/or internet sites.

In addition, there have been many new therapies in the last ten 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 determine what effects they may cause in 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)

Any patient who has had breast cancer is at risk for developing a second breast cancer in the opposite breast. Patients who have had mastectomy are also at risk for developing breast cancer recurrence in either the chest wall, the reconstructed breast, or the axilla (armpit). It is recommended that women who had single mastectomy undergo annual mammograms after treatment for breast cancer. Survivors who had single or double mastectomy should have a yearly breast and/or chest wall exam by a breast cancer specialist (medical oncology provider, radiation oncologist, or breast surgeon).

Radiation to the chest wall after mastectomy may be performed either before or after breast reconstruction surgery. Regardless of this, radiation to the chest wall or reconstructed breast may cause permanent changes in the skin, including a darkening or "tanning." Radiation may also cause difficulty with wound healing, so surgery to the chest wall or reconstructed breast after radiation should be undertaken with caution.

Other long term effects of chest wall irradiation include damage to the nerves, leading to pain or loss of strength or feeling in the arm on the side that was irradiated. Damage to the drainage (lymphatic) system in the area can lead to chronic swelling, called lymphedema. Risk of lymphedema is highest for women who also had surgical lymph node dissections and, to a lesser extent, sentinel node biopsy. A survivor with lymphedema who develops pain or redness in the arm, especially with fever, should be evaluated as these signs may indicate infection.

Survivors of breast cancers, particularly left-sided breast cancers, may be at increased risk of cardiac complications. Please see the description of heart/ cardiovascular late effects for more information.

#### Key Takeaways

- Yearly mammograms (for those who had single mastectomy).
- Annual examination of breast tissue and/or chest wall by breast cancer specialist.
- Caution when surgery is considered after radiation the chest wall or reconstructed breast.
- Consideration of physical/ occupational therapy for arm pain, weakness, or swelling.
- Rapid evaluation for new arm swelling, redness, or pain, especially with fever.

## Heart / Cardiovascular

Potential late effects of radiation fields including the heart include premature coronary artery disease and hypertension (high blood pressure), valve abnormalities, fibrosis or scarring of the cardiac tissue resulting in decreased heart function, pericarditis (inflammation of the heart sac), heart failure and myocardial infarction (heart attack). The actual risk varies greatly depending on the total dose of radiation, number of fractions (doses), amount of radiation actually delivered to the heart, time since radiation and whether or not chemotherapy agents with known cardiac toxicity were also given. Survivors at risk should have a yearly history and physical by a healthcare provider to evaluate cardiac function and blood pressure and should be counseled on lifestyle choices including exercise, tobacco avoidance and a healthy diet. High risk survivors may benefit from yearly EKG and screening echocardiogram to evaluate heart function.

Survivors should also be especially aware of other factors that increase risk of heart disease and death from heart attack. These include high cholesterol, obesity, high blood pressure, diabetes, smoking, and illegal drug use (cocaine). Screening for all of these risk factors can allow for early intervention.

### Key Takeaways

- Avoidance of tobacco and illegal drug use.
- Yearly history and physical exam with monitoring of cholesterol levels, blood pressure, and blood sugar by primary care physician to reduce risk of heart disease/ attack.
- Yearly EKG and/ or echocardiogram for high-risk patients.

## Lung

Radiation fields involving the lung can lead to scarring (fibrosis), inflammation (pneumonitis), and restrictive or obstructive lung disease. Risk for these problems is increased with higher doses of radiation and radiation given in combination with certain chemotherapies (bleomycin, busulfan, BCNU and CCNU) and for those survivors who also had part of the lung surgically removed (lobectomy). Survivors who have had radiation to the lung are strongly encouraged not to smoke, as this can greatly increase the risk of problems. Annual history and physical by a healthcare provider should include a pulmonary exam and review of possible symptoms (cough, shortness of breath, wheezing). Survivors should receive annual flu vaccines and the pneumococcal vaccine. Physicians may consider chest x-rays or pulmonary function tests for those at highest risk or a change in pulmonary status.

Scarring within the lungs can result from radiation, and uncommonly this scarring may affect blood vessels. Any survivor coughing up blood should be evaluated immediately by a healthcare provider, either in the office or the emergency room.

Of note, the Children's Oncology Group recommends survivors not scuba dive without medical clearance from a diving medicine specialist. The National Comprehensive Cancer Network recommends Hodgkins Disease survivors who received chest irradiation consider annual chest x-ray or CT scan to screen for lung cancer, beginning 5 years after treatment. We should note that studies have not yet been done to support this recommendation.

### Key Takeaways

- Annual influenza vaccine.
- Pneumococcal vaccine every 5 years.
- Tobacco avoidance/ smoking cessation.

- Chest X-ray for new cough or shortness of breath.
- Immediate evaluation of hemoptysis (coughing up blood).

## Bone

Damage to the bone from radiation can cause small cracks (fractures) in that bone. The ribs are more susceptible to fracture after radiation, although these fractures will almost always heal normally. If radiation is given in the area of a joint, permanent stiffness, pain and arthritis can develop in that joint.

### Key Takeaways

- Rapid evaluation for fractures after trauma (for example, after a motor vehicle accident).
- Physical/ Occupational therapy for arthritis.
- Non-steroidal inflammatory medicines for arthritis.

## Skin

Radiation can lead to permanent changes in the skin. This can include changes in the color or texture of the skin, scars, and changes in the color, texture of hair or permanent loss of the hair 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. Some patients develop chronic or recurring ulcers of the skin in the area treated. Blood vessels of this skin may become dilated and more noticeable, although this is not harmful. If the skin feels tight or sore, regular use of vitamin E applied to the skin can be helpful.

After radiation the skin is more sensitive to sunlight, and survivors should be especially cautious to use sunscreens when outdoors.

### Key Takeaways

- Diligent use of sunscreen.
- Evaluation by a wound care specialist or surgeon for non-healing ulcers.

## Lymph nodes

The removal of lymph nodes from the axillary (underarm) abdominal or groin areas can lead to decreased drainage in the closest limb causing lymphedema (a swelling of the limb) to result. Survivors who have also received radiation therapy to the area are at greater risk of developing lymphedema which can occur years after therapy. While sentinel node biopsy can decrease the risk of developing subsequent lymphedema, it does not completely eliminate the risk. Lymphedema can cause pain, disfigurement, and functional limitations, and may increase the risk of a serious infection in that limb. A Certified Lymphedema Therapist should be consulted at the first sign of swelling to achieve the best outcomes. Survivors should be aware of this potential complication, given information on self-care, and instructed to notify the healthcare team with any signs of swelling or infection.

Surgery to remove the lymph nodes (or sentinel node) 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. For instance axillary (underarm) lymph node removal can result in these symptoms on the chest wall under the arm (armpit) or in the arm and/or hand on the treated side. Injuries like this could be aggravated by

scar tissue formation after radiation therapy to the area. This type of pain is called nerve pain and is treated with different medications than other types of pain. Survivors with this type of pain may benefit from a consult with a pain specialist.

### Key Takeaways

- Radiation increases the risk of lymphedema over surgery alone. A Certified Lymphedema Therapist should be consulted at the first sign of swelling for best outcomes.
- Survivors should be educated about self care and to notify the healthcare team with any signs of infection. Instructions for survivors on risk reduction are available from the NLN.
- Radiation and/or surgery can damage nerves, which can be further aggravated by scar formation and result in neuropathic pain. Survivors with this pain may benefit from seeing a pain specialist.

## Surgery Side Effects

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### Sentinel Node Biopsy

The removal of lymph nodes from the axilla (underarm), abdomen, or groin area can lead to decreased drainage in the closest limb, causing lymphedema (a swelling of the limb) to result. In the case of head and neck cancers, the swelling can involve the neck and face. Survivors who have also received radiation therapy to the area are at greater risk of developing lymphedema, which can occur years after therapy. While sentinel node biopsy can decrease the risk of developing subsequent lymphedema, the risk is not completely eliminated. Lymphedema can cause pain, disfigurement, functional limitations and increase the risk of a serious infection in that limb. A Certified Lymphedema Therapist should be consulted at the first sign of swelling to achieve the best outcomes. Survivors should be aware of this potential complication, given information on self-care and instructed to notify the healthcare team with any signs of swelling or infection.

Signs of lymphedema may include the following changes in the area near surgery (arm, leg, abdomen, genitals): full or heavy feeling, skin changes (reddened, warm, cool, dry, hard, stiff), aching/discomfort, tightness, or less movement/flexibility in nearby joints. You may also experience difficulty fitting into clothes like the sleeve of a jacket or pant leg, or feel your socks are too tight. In addition, you may notice jewelry feels tight even though you have not gained any weight. Lymphedema can occur right after surgery, weeks, months, or even years later. The possibility of developing lymphedema continues throughout a person's lifetime. Survivors should be vigilant in monitoring for early signs of swelling and practice prevention. If swelling develops, prompt, proper management and therapy allows for the best outcomes.

To help prevent and control lymphedema, survivors should try to avoid infections, burns, cuts, excessive hot/cold or injury to the limb that is at risk. Avoid insect bites by using insect repellent. Use lotion to prevent dry, chapped skin. Use sunscreen with SPF 15 or higher and try to avoid the sun during the hottest time of day. Avoid pressure or constriction of the limb. Avoid tight fitting clothes and jewelry.

Those at risk for lymphedema can and should exercise. Start with low intensity exercise and gradually increase intensity while monitoring for changes in your limb including swelling or redness. If any swelling or redness occurs, stop the exercise and consult your physician. The person at risk for lymphedema should consider wearing a compression garment with vigorous or very strenuous exercise.

Whenever possible, have blood drawn, IVs placed, and shots/vaccinations given and blood pressure taken



in the unaffected arm. For more information on what you can do to help prevent lymphedema, look at the Lymphedema Self Care Tip Sheet on the Oncolink website. The National Lymphedema Network is also a great resource for information.

Surgery to remove the lymph nodes (or sentinel node/s) 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. For instance, axillary (underarm) lymph node removal can result in these symptoms on the chest wall, under the arm (armpit) or in the arm and/or hand on the treated side. Injuries like this could be aggravated by scar tissue formation after radiation therapy to the area, which can develop years after therapy. This type of pain is called nerve pain and is treated with different medications than other types of pain. Survivors with this type of pain may benefit from a consult with a pain specialist.

### **Key Takeaways**

- Report any signs of swelling in the at risk limb to your healthcare provider, and see a certified lymphedema therapist promptly if these symptoms develop.
- Practice preventive measures to decrease the risk of developing or worsening lymphedema.

## **Lumpectomy**

Surgery for breast cancer can include mastectomy (removal of the entire breast) or lumpectomy (sometimes called breast conserving surgery, where only the breast mass (lump) and a surrounding area of normal tissue is removed). The surgeries can result in cosmetic deformities. In some cases, these can be corrected with breast reconstruction performed by a plastic surgeon. There is a risk of nerve damage during breast surgeries, which can lead to pain in the chest wall and/or pain and tingling in the arm/hand on the side of the surgery. Injuries like this can be aggravated by scar tissue formation after radiation therapy to the area, which 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. Survivors who develop chronic pain may benefit from a consult with a pain specialist.

Those who undergo a modified radical mastectomy, and sometimes those undergoing lumpectomy, may also have lymph nodes removed during surgery. The removal of lymph nodes increases the risk of developing lymphedema. In addition, patients, who have undergone lymph node dissection, may also develop nerve damage (as described previously), pain in the shoulder, or limitations in movement of the arm and shoulder. These complications may be temporary, but could become permanent. Exercises to promote shoulder mobility may be of help, and can be described and taught by a physical therapist.

Survivors of breast cancer should speak with their health care provider regarding the possibility of a genetic or family syndrome. If there does appear to be a family history or possible genetic link, genetic counseling and testing may be warranted for the survivor and his or her family.

### **Key Takeaways**

- Be vigilant for signs/symptoms of lymphedema and ensure early and proper management.
- Remember to do monthly self-breast exam. Get a mammogram on remaining breast(s) every year.
- Report pain the breast or chest wall to your healthcare provider.
- Consider physical therapy for decreased range of motion in the shoulder.

# 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 21 using the following methods:

- Age 21-29: Pap testing done every 3 years. HPV testing is used only to follow up abnormal Pap results.
- Age 30-65: Pap testing and HPV test done every 5 years. Alternatively, a woman could have a Pap test alone every 3 years.
- Over age 65: women who have had normal Pap results can stop testing all together. Women who have had a history of a serious cervical pre-cancer should continue to be tested for 20 years after that diagnosis, even if this continues past age 65.
- Women who have had their uterus & cervix removed for reasons not related to cervical cancer and have no history of cervical cancer or pre-cancer do not need testing.
- Women who have had HPV vaccination should still have Pap testing per the above guidelines.

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 50 should undergo routine screening for colon and rectal cancer. 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 50 (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:

- 55 to 74 years of age and in fairly good health
- Have at least a 30 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 30 years has a 30 pack-year smoking history, as does someone who smoked 2 packs a day for 15 years.)

Screening is done with a low-dose CT scan (LDCT) of the chest. If you fit the list above, you and a doctor should talk about whether you want to start 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 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 (10am-4pm, 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.

## 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 the survivor to be back to doing the things they did before treatment, with the same vigor. Many survivors report significant fatigue years after completing therapy, which can be extremely frustrating for the survivor and those around them. There have been many studies examining fatigue and ways to combat it during treatment, but there is little to provide guidance for dealing with fatigue after therapy. 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 light exercise can aid in relieving fatigue during treatment, so it is possible that this could help post treatment. Talking with other survivors may help in finding ways to deal with fatigue. Most importantly, you should understand it is normal and you will need to give your body time to slowly return to your former energy levels. With a lack of available interventions proven to relieve fatigue, survivors may need to learn to work around it in a sense. A wise survivor once dubbed herself the "master of fatigue" because, she stated, "I had learned how to outsmart it". By thinking of her energy as a full bowl of candy each morning, and each task a certain number of candies. She only had so many candies each day, so tasks needed to be prioritized and balanced with the amount of candies left in her bowl. By learning to manage tasks, group errands, make lists, prioritize and delegate, you can, to an extent, outsmart your fatigue.

## Life After Cancer

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### Life After Cancer

After active treatment is complete, you will begin a plan for follow-up care. This will involve less frequent visits to the oncology team, which for many 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 emotional reaction at this time. They anticipate jumping for joy and throwing survival parties, and instead find themselves crying in the parking lot after their last treatment, feeling vulnerable in unexpected ways. Some find it disconcerting that they are no longer receiving active treatment to attack rogue cancer cells; furthermore, their treatment team is no longer giving them much needed daily or weekly support. Early cancer survivors can feel fear, sadness, anger, isolation and grief.



These feelings can co-exist with a sense of relief, gratitude, and an enhanced sense of capacity to face adversity.

Completion of therapy is a time when friends and family may say, "Congratulations" and "You must be glad to be done", though you may be feeling uncertain about this milestone. Friends, family and even the oncology team can be caught off guard 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 here are a few tips to help you deal with it.

For starters, be assured that your oncology team is always there if concerns arise. Protocols 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.

Friends and family will say it must be nice to be getting back to normal. But as any cancer survivor will tell you, things have changed, and so has the 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 a few folks you have met along the way). Email and the Internet have created a wonderful support for all sorts of concerns, and survivorship is no different. Visit the [Association of Cancer Online Resources](#) to find an email group that fits your needs or search the Internet for cancer survivor support. [CancerCare](#) provides support groups and professional counseling over the phone or online. Many cancer centers and advocacy organizations offer support groups for survivors to address their specific concerns after therapy. 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. Buddy programs are offered by [Imerman Angels](#), [Cancer Hope Network](#), and many other disease-specific advocacy groups.

Cancer survivors face daunting tasks: finding meaning in illness, restoring a sense of identity and purpose, and coping with uncertainty. How one begins to meet these challenges is unique to each survivor. For some, recovery from the trauma of cancer and its treatment can be made more difficult by the late medical complications of treatment, which can affect quality of life. Remind yourself of the strength you demonstrated in having met the challenges of cancer treatment. Setting new goals and turning to spirituality are possible strategies for coping. Using artistic expression such as painting and writing can be helpful tools to work through your emotions. When emotions become too overwhelming, it may be helpful to seek a referral to a mental health professional. Signs of persistent depression and anxiety interfering with sleep and daytime function, hopelessness, and suicidal thinking are indicators that professional help is needed. Ask your oncologist to recommend a psychological professional, or visit the [American Psychosocial Oncology Society](#) (or toll-free 866-276-7443) to find a mental health professional familiar with cancer-related distress in your area.

Completing treatment can also present other challenges. Your family or employer may expect things to pick up where they left off. Resuming your previous activities may not be as easy as it sounds. Many survivors suffer from fatigue or limited energy for months, or even years, after therapy. 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. Some people describe their 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.



The issues we have discussed thus far will generally resolve, or at least improve, in the months following treatment. But there are many issues that can affect survivors in the long term, including health issues related to treatment, as well as financial (employment and insurance) and personal (fertility, sexuality and relationship) issues.

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, because 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? Learn what your risks are based on the treatment you received, learn what you can do to prevent them, if possible, and learn how to monitor for them. You have taken the first step by developing a survivorship plan of care. 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 personal 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).

There are many resources to help survivors, but it can take some homework to find what you need. In dealing with employment, disability and insurance issues, you should learn about your rights and your employer's responsibilities under the law. OncoLink's [section on financial and insurance issues](#) may be helpful. The [National Coalition for Cancer Survivorship](#) and the [American Cancer Society](#) websites have financial and insurance information for survivors. The [Cancer Legal Resource Center](#) provides information on cancer-related legal issues, including insurance coverage, employment and time off, and healthcare and government benefits. [Cancer and Careers](#) is a resource for all things employment-related, from time of diagnosis well into survivorship.

Personal 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 issues. [Us Too](#) and the [American Cancer Society](#) provide fertility and sexuality resources.

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. For those that find things more difficult, a mental health provider can help you cope with the physical and emotional trauma cancer brings and determine how to move forward, whether with a partner or looking for one. Look for a therapist with expertise in working with people with cancer and/or sexual and relationship issues.

All of this can be a bit overwhelming, but the fact that there are over 14 million cancer survivors in the United States today is 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.