



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

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

## Your Summary

Welcome to your personalized Smart ALACC Care Plan. This plan gives you information about the health risks you may face as a result of cancer therapies, and recommendations on how to manage your long-term health.

As you read this, keep in mind:

- While going through your care plan, 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 current research concerning childhood cancer survivors. This area is continually growing. Information provided in care plans will be updated periodically. That means, you might want to create a new care plan every few years.

## You received the following treatments for Rhabdomyosarcoma

- Cyclophosphamide (Cytoxan®, Neosar®)
- Dactinomycin (Cosmegen®)
- Vincristine (Oncovin®, VCR)
- Radiation to the pelvis
- X-ray based radiation- IMRT

## Coordinating Your Care

As a survivor, you may see many different doctors and health care practitioners, including a cancer specialist, primary care provider (PCP), or other specialists.

- As a survivor, it is important that you keep a treatment summary and a copy of your care plan that is easily accessible. You may also include your doctor's information and current medications. Bring this information to your medical appointments.
- This Care Plan can help you and your medical team understand what issues to look for, and how to handle them.
- Knowing this information, and discussing it with your medical teams, can help you all work together to manage your health and well-being.

Other tips:

- Visit the [OncoPilot](#) section for forms you can use to organize your medical information.
- Visit our [list of clinics here](#) to find a long-term follow-up clinic (this list is updated periodically). Going to a survivorship clinic will give you a chance to discuss your treatment and the possible risks, and can provide helpful information to your primary care team.

# What's In Your Care Plan

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## Follow Up Care for Rhabdomyosarcoma

After finishing treatment, you will have medical exams and imaging tests (which may include chest x-rays, CT scans, MRI scans or other studies) to monitor for your cancer coming back. In general, these exams and/or tests will be more frequent (example: every 3 months) right after treatment and are spaced out (to every 6 months, and then yearly) over time. In general, the further you are from treatment, the lower the risk of recurrence, which is why these tests are spaced out over time - and then not needed at all to look for the primary tumor coming back!

You and your healthcare team should begin to discuss keeping you healthy in the long-term ("survivorship care"). Survivorship care includes the things discussed in this plan and may involve seeing other healthcare teams (like doctors or nurses who follow cancer survivors, primary care teams or specialists).

Each pediatric cancer survivor is unique because of the cancer you had, the different treatments you got and how your body tolerated them. A survivorship care plan is meant to help you navigate your needs as you transition away from regular oncology visits. The goal of survivorship care is to meet your needs - physical and emotional, prevent and monitor for late effects, and to help you thrive after cancer.

# Risks Related to Medications

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## Risk of Bladder or Urinary Tract Toxicities

The risk for bladder and urinary tract toxicities is higher if you got cyclophosphamide (at doses > 8g/m<sup>2</sup>), ifosfamide, and/or radiation to the abdomen or pelvis. Late effects to the urinary tract can include hemorrhagic cystitis (bleeding inside the bladder) and scar tissue in the bladder (causing you to be able to hold less urine). Symptoms of hemorrhagic cystitis are urinary frequency (going often) and urgency (needing to go right away), blood in the urine, and pain when urinating. Bladder scar tissue can cause difficulty urinating, frequency (going often), or urgency (needing to go right away). There is also a small risk for bladder cancer after treatment with cyclophosphamide, ifosfamide, or radiation to the abdomen or pelvis. If you have any of these symptoms, you should report them to your healthcare provider right away. Alcohol use and smoking can also cause problems with bladder function, so these should be avoided.

### Key Takeaways

- Avoid alcohol and smoking.
- Tell your healthcare provider if you have any of the following symptoms:
  - Pain when urinating.
  - Urinary hesitancy (difficulty starting the stream).
  - Urinary urgency or frequency.
  - Getting up in the middle of the night to urinate.
  - Blood in your urine.

## Risk of Developing Bladder Cancer

Cyclophosphamide can lead to the development of bladder cancer. Your risk is higher if you also got radiation therapy to the abdomen or pelvis. Symptoms of bladder cancer include blood in the urine, urinary frequency (going often) and urgency (needing to go right away), urinating at night, and incontinence (unable to hold your urine). Tell your healthcare provider if you have any of these symptoms. Alcohol use and smoking can also lead to bladder cancer, so these should be avoided.

### Key Takeaways

- Avoid alcohol and smoking.
- Report the following symptoms to your healthcare provider:
  - Pain when urinating.
  - Urinary hesitancy (difficulty starting the stream).
  - Urinary urgency or frequency.
  - Getting up in the middle of the night to urinate.
  - Blood in your urine.

## Peripheral Neuropathy

Peripheral neuropathy is caused by irritation or damage to nerves, leading to feelings of numbness, “pins and needles,” tingling, burning, or a feeling of weakness or heaviness in the arms or legs. Neuropathy can cause trouble with fine motor skills such as buttoning a shirt, sensation of hot or cold (causing a safety

hazard), or difficulty walking. For some people, neuropathy goes away within weeks to months after ending therapy or stopping the medication that caused the problem. For others, neuropathy becomes chronic, and you may need physical and occupational therapy, medications, and changes in your environment to keep you safe.

Medications that are not typically thought of as pain medications are often used to manage the pain caused by neuropathy. These could be tricyclic antidepressants, gabapentin and pregabalin. If the pain is not well managed, seeing a pain specialist or physical/occupational therapist may be helpful.

Neuropathy does not typically develop as a late effect, so if you have symptoms suggestive of neuropathy months to years after therapy, other causes should be considered.

### Key Takeaways

- Peripheral neuropathy is caused by irritation or damage to nerves, leading to feelings of numbness, “pins and needles,” tingling, burning, or a feeling of weakness or heaviness in the arms or legs.
- Peripheral neuropathy can be a long-lasting side effect that can require physical therapy, changes in your daily life for safety, and managing pain with medication.

## Risk of Developing Osteoporosis

Osteoporosis is a decrease in bone density (thinning of the bones) that can lead to fractures (broken bones). The risk for osteoporosis 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 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 had a gastrectomy (removal of the stomach).
- Several types of chemotherapy have been found to contribute to bone loss, including Cytoxan, cisplatin, carboplatin, ifosfamide, doxorubicin, methotrexate, and possibly imatinib.
- General factors that increase the risk of osteoporosis include: being over the age of 50, smoking, drinking too much alcohol, not exercising, and some chronic health conditions.

There are things you can do to lower your risk of a fracture and strengthen your bones:

- 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 citrate supplements. Your body does not absorb calcium supplements well, so spread the dose out by taking 1 tablet several times a day, instead of all at once. If you take Synthroid/ Levothyroxine

(thyroid hormone), separate it from calcium doses by at least 4 hours.

- Take 800-1000 IU of vitamin D-3 daily.
  - Your healthcare provider may check blood levels of vitamin D with the 25-OH Vitamin D blood test.
  - Do not take more than 2000 IU of vitamin D3 a day, unless directed by your healthcare provider.
- Weight-bearing exercise and strength training can improve your bone strength.
  - Before you start an exercise program, check 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 exercises like leg extensions, calf raises, leg curls, chest press, latissimus pulldown, overhead press, row machine, and curl-ups, 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>. 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.
  - 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. Learn more about how to get started [on OncoLink](#).
- Your provider may order a DEXA scan, which is a test used to measure the thickness (density) of your bones.

### Key Takeaways

- You should avoid smoking, caffeine, and excessive alcohol intake.
- Perform weight bearing and strength training exercises 2-3 times per week.
- Aim for a 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 for osteoporosis with a DEXA scan.

## Raynaud's Phenomenon

Raynaud's phenomenon is a condition that causes blood vessels in certain areas of the body to constrict or spasm, causing numbness and cold feeling in that area. This may happen when the area is exposed to cold or can be triggered by stress. Most people have symptoms in their hands/fingers or feet/toes, but it can be in the nose, earlobes, lips, or cheeks. Spasm and constriction of the blood vessels leads to decreased blood flow to that area, resulting in a lack of oxygen, causing tissues to appear pale or blue in color. Once the attack is over, the tissues may appear red from the rush of blood back into them.

Survivors who have gotten vincristine, vinblastine, or vinorelbine are at the highest risk for having this issue. Symptoms can start during, or months after treatments are completed. For some people, the symptoms will go away over time, but for others they do not. In some cases, Raynaud's is seen along with hypertension or erectile dysfunction in men because those can also be caused by spasm of the blood vessels.

You should avoid exposing the affected area to cold as this can trigger an attack. Wear gloves if going out in the cold and your hands are affected. Nicotine can also constrict blood vessels, so smoking or vaping should be avoided. Some medications can cause constriction of the blood vessels, including pseudoephedrine, birth control pills, and certain heart and blood pressure medications. Talk to your healthcare provider if you are taking any of these medications and are experiencing Raynaud's phenomenon. Medications that dilate blood vessels may be used to control symptoms in severe cases, but these have their own side effects. You should also have your blood pressure checked every year.

### Key Takeaways

- Raynaud's phenomenon is a condition that causes blood vessels in certain areas of the body to constrict or spasm, causing numbness and cold feeling in that area.
- Avoid smoking and medications that constrict blood vessels.
- Protect affected areas from cold exposure.
- Have your blood pressure checked every year.

## Skin Toxicities

Some cancer medicines can cause your skin or nails to darken all over, or in spots. The change in skin color tends to fade over time but can be permanent. Many people will have very dry or scaly skin while on cancer treatment. Use a mild soap and a hydrating lotion regularly.

Your nails may become weak and brittle. Keep your nails trimmed to avoid them ripping. Do not use fake nails or gel manicures as these can further damage your nails. Taking care of your skin and nails can help them recover. Protect your skin from the sun with SPF >30, protective clothing, and avoid the sun during peak hours (10am-3pm).

### Key Takeaways

- Care for your skin with mild soaps and hydrating lotions.
- Protect your skin from sun damage.

## Learning Differences

Many survivors who have previously had or are currently undergoing chemotherapy report cognitive changes. These changes include difficulty with short term memory, multi-tasking, new learning, reading comprehension, working with numbers, and a decrease in the ability to concentrate. 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.

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 check for these problems and treat them. 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 by taking a thyroid hormone medication. Survivors who are depressed or are experiencing anxiety would benefit from seeing a psychiatrist, psychologist, or other mental health professional experienced in working with cancer patients or survivors.

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 things being studied are methylphenidate (Ritalin), modafinil

(a medication approved to treat narcolepsy), various antidepressants, herbal therapies (such as ginkgo biloba, ginseng, and certain amino acids). Neurocognitive testing and cognitive rehabilitation may be helpful. Cognitive rehabilitation programs that use exercise, tasks that use memory, and puzzles to "rehabilitate" one's mind may also be helpful. These programs are 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 make cognitive problems worse, so be sure to get enough sleep, get regular exercise, and eat a healthy diet to combat fatigue.

### Key Takeaways

- Let your healthcare team know if you have trouble with short term memory, multi-tasking, new learning, reading comprehension, working with numbers, or a decrease in concentration that is affecting your day-to-day life.

## Fertility Concerns for Female Survivors

Fertility (or the ability to have children) after cancer therapy is a very complex topic. It is related to the doses and types of medications you got, radiation and/or surgery that may have affected reproductive organs, and your age at the time of treatment. With all of these things, it is sometimes hard to predict a survivor's reproductive health. Regardless of what treatment you got, all survivors should use protection when sexually active if pregnancy is not desired, and to protect against sexually transmitted infections. Survivors who want to know if they can get pregnant should see a reproductive specialist who has experience working with cancer survivors. Specialists can do tests to evaluate fertility.

Chemotherapy meds that most often cause infertility are alkylating agents (including cyclophosphamide, cisplatin, carboplatin, melphalan, and ifosfamide), and the risk is higher with higher doses of these medications. High dose chemotherapy, used in preparation for stem cell/bone marrow transplant, almost always cause the ovaries to stop working and in turn, infertility. Radiation to the abdomen, pelvis, brain, or full body (TBI) can also impact fertility.

Even if you have normal periods after cancer therapy you should be aware that you might still have earlier than expected menopause, which can affect family planning. When pregnancy does occur, you may need to be followed by a "high-risk" obstetrician depending on what treatments you had, and planning for this may be important.

### Key Takeaways

- Survivors wishing to become pregnant should consider seeing a fertility specialist familiar with cancer survivors.
- All women should use protection when sexually active if pregnancy is not desired, and to protect against sexually transmitted infections.

## 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.

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. The medication 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.
- The risk is higher in the first 10 years after your treatment.
- Report the following symptoms to your healthcare provider promptly:
  - feeling more tired or weaker than usual
  - looking pale
  - shortness of breath
  - loss of appetite
  - weight loss
  - chills, fevers, night sweats
  - painless swelling of a lymph node
  - easy bruising, nose bleeds, or bleeding from the gums
  - pain in your bones
- Consider having a complete blood count with differential checked by your healthcare provider if you experience any of the above symptoms.

## Understanding New Research and Therapies

Most chemotherapy medications have been studied extensively, and their side effect risks are well-understood. Research is continuing, however, and new information may become available. You should periodically talk to your healthcare team about new information that becomes available for cancer survivors.

In addition, there have been many new therapies in recent years, including many 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.

You can revisit Smart ALACC to create an updated plan periodically and visit the [Children's Oncology Group Long Term Follow-Up website](#) to learn about any 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 differ based on the areas of the body that were exposed to radiation. This is impacted by the location and size of the radiation field, as well as the type of radiation and the radiation techniques that were used. Newer radiation techniques help limit exposure of normal organs and tissues, but it is not always possible to prevent all exposure and still allow the radiation to effectively treat the cancer.

## Cancer After Radiation Treatment

There is a chance of developing a tumor (either cancerous or non-cancerous) in the area that was treated with radiation. Cancers can develop in the skin, bone, or other tissues in the area where you had radiation treatment. These are called secondary cancers. You should report any changing moles, skin lesions, bone pain, or a lump in the treated area to your healthcare team.

You can help prevent future cancers by checking your skin in the treatment area each month, protecting your skin with sunscreen (SPF >30), not using a tanning booth, not smoking, and having any recommended screening tests. If the area you were treated has any specific cancer screening guidelines, it will be discussed in this care plan.

### Key Takeaways

- Protect your skin from the sun by seeking out shade, using sunscreen, and not using tanning booths.
- Report any changes in moles, skin lesions, bone pain, or lumps found in the radiation treatment area.

## Bone Health

Damage to the bone from radiation can cause small cracks (fractures) in that bone or changes in the length of the bone if the radiation is given before you stop growing. If radiation is given around a joint, permanent stiffness, pain and arthritis can develop in that joint. Radiation to the spine can cause growth changes, including loss of height and scoliosis. If you had radiation near your spine you should have your spine examined yearly.

You can support your bone health by getting enough calcium and vitamin D and doing regular weight-bearing exercise. Areas of bone that have been exposed to radiation may be more prone to injury. If you have any new or worsening pain or trauma to the area, tell your healthcare provider.

### Key Takeaways

- If you experience any kind of trauma involving the area that received radiation (for example, a fall), you should be seen by a provider to be sure you have no broken bones.
- Physical/ Occupational therapy can be helpful for managing arthritis.
- Non-steroidal inflammatory medicines can also be helpful for managing arthritis.

- You may need to see an orthopedic doctor or physical/occupational therapy if your limbs are not the same length and it is affecting function.
- If your spine was in the treatment field, it should be examined every year until you have stopped growing.

## Maintaining Healthy Skin

Radiation can lead to permanent (won't go away) changes in the skin. This can include changes in the color or texture of the skin or scars. There can also be changes in the color and texture of hair or permanent hair loss in the treated area. The soft tissue and muscles under the skin can develop scarring and/or shrinkage, which can cause the area to be less flexible, difficult to move, or to have chronic swelling. Some patients develop chronic or recurring ulcers of the skin in the treated area. Blood vessels of the skin in the area may become more noticeable (visible), although this is not harmful. If the skin feels tight or sore, regularly putting vitamin E on your skin can be helpful.

After radiation, the skin is more sensitive to sunlight, and you should be sure to use sunscreen with a 30 SPF or higher when outdoors.

### Key Takeaways

- You should wear sunscreen (SPF 30 or higher) anytime you are outdoors.
- You should see a wound care specialist or surgeon if you have any skin wound or ulcer that does not heal.

## Bowel Health

The bowel is very sensitive to radiation, and several late effects may occur after radiation to the rectum, colon, or small bowel:

*Scar tissue and strictures (narrowing)* of the bowel can lead to bowel obstruction (blockage), which is most common in people who had surgery and/ or radiation to the abdomen. If you have any signs of bowel problems, tell your healthcare provider. Things to report include abdominal pain, constipation, vomiting, weight loss, and bloating. If you have severe abdominal pain with vomiting and constipation, you should be seen by a provider right away. If you have a bowel obstruction, you should be followed by a gastroenterologist (GI doctor) or surgeon.

*Ulceration and bleeding* of the bowel can occur after radiation. Bowel tissue is very delicate and can be damaged by radiation. If you have bright red blood in your stools, toilet water, or on toilet paper, or dark black stools, you should tell a provider right away. These can be signs of radiation colitis or proctitis (irritation of the bowel or rectum) and you may need a colonoscopy to determine the cause.

*Chronic diarrhea or poor absorption of nutrients* can result from radiation to the bowel. If you develop diarrhea with weight loss or malnutrition, you should be seen by a gastroenterologist. Anti-diarrheal or anti-spasmodic medicines may be helpful. It can be helpful to see a dietician if you continue to lose weight or have electrolyte abnormalities (found with blood tests).

*Fistula formation:* A fistula is a connection between two body cavities that do not normally connect. A fistula can form between the bowel and bladder, bowel and female reproductive system (uterus/ vagina), or the bowel and the skin. If you have a fistula between the bowel and bladder you may pass gas or stool through the urethra (the tube that drains urine). Any abnormal passage of urine, feces, or blood should be

reported to a healthcare provider right away and you will likely need to be evaluated by a surgeon.

*Colon Cancer Screening:* Radiation to the bowel can lead to colon cancer. You should have a colonoscopy or DNA stool testing to screen for polyps or colon cancer. The Children's Oncology Group guidelines for childhood cancer survivors recommend that if you got abdominal radiation, you should get a screening colonoscopy 10 years after radiation or at age 35 (whichever is later). You should repeat the colonoscopy every 5 years. If you are unable to have a colonoscopy, you can get a multitarget stool DNA test every 3 years instead.

Screening of the general population begins at age 45. Depending on your age during treatment, the amount of radiation you received, and your family and health history, you and your provider should discuss when to begin screening. People who may need earlier screening are those with irritable bowel disease, chronic diarrhea or bleeding, ulcerative colitis, familial colon cancer syndromes, or previous gastrointestinal cancers or polyps.

### Key Takeaways

- See a provider right away if you have severe abdominal pain, especially if you also have nausea/vomiting and constipation or if you are bleeding from the rectum or have dark (black) stools.
- Anti-diarrheal medicines can be helpful for chronic diarrhea.
- You should see a dietitian if you have unintended weight loss.
- A screening colonoscopy is recommended for all people beginning at age 45. For those who received abdominal radiation, screening colonoscopy is recommended beginning 10 years after radiation therapy or at age 35, whichever is later, with repeat colonoscopy every 5 years.

## Female Pelvis

Radiation to a girl or woman's pelvis can cause long term changes to the vagina, uterus, and ovaries. The ovaries are responsible for both egg production and the production of female hormones that support growth, puberty, and menstruation. A female baby has all of the eggs in her ovaries that she will have for her lifetime. These eggs can become an embryo when fertilized by sperm, making a baby. When the ovaries are exposed to radiation, this supply of eggs (oocytes) can be damaged. This means that a woman or girl who had pelvic radiation may have fewer healthy eggs and have trouble getting pregnant. The risk of fertility problems goes up with higher doses of radiation.

Ovaries are also responsible for making hormones. After radiation that involves the ovaries, girls who have not yet gone through puberty are at risk for late-onset puberty, or for not going through normal puberty at all. Young women who have gone through puberty and started menstruating before treatment are at risk for decreased ovarian reserve (premature menopause).

You should follow up regularly with your healthcare provider. Your growth should be monitored as well as the stage of puberty you are in. If you do not experience signs of puberty by age 13, begin puberty but it does not progress, or have abnormal menstrual patterns or symptoms of menopause, you should be seen by an endocrinologist or reproductive endocrinologist. If you are sexually active, you should use contraception (birth control) if you DO NOT wish to be pregnant. If you would like to be pregnant but are not able to conceive, you should see a reproductive endocrinologist.

If you are found to have low levels of ovarian hormones, you should undergo yearly bone density testing (DEXA scan), due to the risk of osteoporosis.

Radiation to the uterus (womb) can lead to a decrease in the size of the uterus, a decrease in elasticity (stretch), and scar tissue forming. These changes in the uterine muscle put you at a higher risk of miscarriage, preterm labor, and having a baby born at low birth weight. If you wish to become pregnant, you should see a high-risk pregnancy specialist. An ultrasound of the uterus and other reproductive organs may be helpful. Women who become pregnant after pelvic radiation should receive high-risk obstetrical (OB) care.

You may suffer from vaginal dryness and some other symptoms that are often part of menopause – these can include atrophy (a decrease in the size of your vagina) and vaginal pain. Using personal lubricants and moisturizers can be helpful and can make intercourse more comfortable. Regular use of vitamin E on and around the vaginal tissue may help to strengthen the tissue and reduce friction to sensitive tissue. Scarring in the vagina may cause the size of the vagina to decrease. Using vaginal dilators, which are placed in the vagina for short periods of time, is recommended for all females who had radiation to the vulvar or vaginal pelvic area. Dilators help keep the vaginal space open, allowing menstrual blood to drain out of the uterus. If dilator or tampon insertion is difficult, seeing a gynecologist or pelvic floor physical therapist may be helpful. Lastly, if you are experiencing chronic pain (continuous or on and off) in the vulva, which can be a sign of vulvar pain syndrome, tell your healthcare provider. Medicines like amitriptyline (tricyclic antidepressants) and working with a mental health provider (psychologist, therapist) may be helpful in managing vulvar pain.

Radiation to the groin can cause swelling (lymphedema) in the groin or legs. Tell your provider if you have any swelling. Starting physical therapy at the first sign of swelling can help with the management of lymphedema.

### Key Takeaways

- The use of personal lubricants and/ or vitamin E can help if the vaginal area is painful, dry, or tender during intercourse.
- Vaginal dilators should be used to help keep the vagina open.
- Talk with your provider about treatment for vulvar pain.
- A physical therapist can help with managing the swelling of genitals or legs.
- You should see a high-risk pregnancy specialist if you wish to become pregnant.
- You should see an endocrinologist if you do not go through puberty by age 13, or if you have a change in menstrual patterns or symptoms of menopause after treatment.
- You should have a bone density evaluation if you have any deficiencies in ovarian hormones.

## Lymph Nodes

Having your lymph nodes removed from the axillary (underarm), abdominal (belly) or groin areas can lead to decreased drainage in the closest limb/area which can cause lymphedema (a type of swelling). If you got radiation therapy to the area where lymph nodes were removed, you are at a higher risk for lymphedema. This can occur years after therapy. Sentinel node biopsy is a type of lymph node removal that reduces (but does not eliminate) the risk of lymphedema.

Lymphedema can cause pain, changes in your appearance or ability to do daily tasks, and can increase the risk of a serious infection in that limb. You should see a Certified Lymphedema Therapist at the first sign of swelling for the best outcomes. You need to know about this potential complication, understand how to reduce your risk, how to care for the area, and to notify your healthcare team if you have 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. Nerve damage can cause pain, numbness, tingling, and decreased sensation or strength in the area or nearby 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 made worse by scar tissue forming 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 seeing a pain specialist.

### Key Takeaways

- Radiation to an area increases the risk of lymphedema. You should see a Certified Lymphedema Therapist at the first sign of swelling.
- You should be taught how to care for the area and to notify your healthcare team if there are any signs of infection. You can learn about self-care on OncoLink.
- If you develop swelling, numbness, tingling, pain or loss of strength in the treated area, tell your healthcare provider.

## Bladder Health

Radiation fields that include the bladder can lead to bladder health concerns. The bladder can develop scar tissue, which can result in your bladder being able to hold less urine.

If you get radiation along with chemotherapy medicines known to cause bladder damage (cyclophosphamide, ifosfamide), you are at risk for hemorrhagic cystitis (bleeding from the bladder lining). Symptoms of hemorrhagic cystitis are frequent urination (needing to go often) and urgency (needing to go quickly), blood in the urine, and pain. You should report these symptoms to your provider right away.

Radiation to the bladder can hurt nerves that control bladder function. This is called neurogenic bladder and can cause the bladder to not empty completely or need to be emptied more frequently. It can also make you more likely to get urinary tract infections. Tell your provider if you have urinary burning, frequency, needing to wake up at night often to urinate, incontinence of urine (can't control), fever, pain with urinating or blood in the urine.

Radiation to the bladder can increase your risk of developing bladder cancer. Symptoms may include blood in the urine, urinary frequency and urgency, urinating at night, and incontinence. Tell your provider if you have any of these symptoms.

Late effects on the bladder all have similar symptoms. You may have urine tests or cystoscopy (inserting a small tube with a camera into the bladder) to figure out what is causing your symptoms. It is best to minimize alcohol use and avoid smoking, because these irritate the bladder and may increase your risk of bladder cancer.

### Key Takeaways

- Report any new or worsening bladder symptoms to your provider.
- Avoid alcohol use and smoking because these can further irritate your bladder.

## Taking Care of Your Health After Cancer

People often wonder what steps they can take to live healthier after cancer or to prevent cancer from coming back. There is no supplement or specific food you can eat to assure good health, but there are things you can do to live healthier, which may lower the risk of cancer and other diseases in the future.

## **A Note on Genetics**

Many survivors have questions about the genetics of their cancer and what that means for them or their family members. It is common for families to have more than one person who is affected by cancer. Most of the time, this is a random occurrence, but some cancers are known to be associated with specific genes (part of a person's DNA), that can be passed from one family member to the next generation.

Healthcare providers will assess this risk by asking about your personal and family history of cancer. If you have concerns that cancer "runs in your family" you should speak to your care team and they can help determine if there is a known risk for you. To help, you should find out the types of cancer in your family, at about what age people had cancer, if any family members had more than one cancer, and what other risk factors were involved (like smoking).

Very few cancers are known to have this type of genetic risk (less than 10%). If your healthcare providers have concerns, you will be referred to a genetic counselor for further testing.

Often, survivors of childhood cancer will have additional questions about the risk of cancer (or other problems like birth defects) for their children because of their history of cancer and cancer treatment. Luckily, many studies have shown that there is no increased risk of childhood cancer or birth defects in children of cancer survivors just because their parents had cancer unless they have a genetic abnormality linked to cancer.

## **Cancer Prevention and Screening After Cancer**

For anyone who has been treated for one cancer, one goal of medical care should be to prevent other cancers or detect them early!

### **Are cancer survivors at increased risk of cancer?**

Some studies have found that cancer survivors are more likely to develop another cancer when compared to someone who has never had cancer. In some cases, a cancer treatment can increase the risk of another cancer, called "secondary cancer." The increased risk of developing another cancer may also be related to other risk factors (smoking, for example), or a genetic predisposition in certain individuals. But in many cases, the reason for the increased risk is unclear. While this may sound scary, it is a reminder of the importance of cancer screening and maintaining a healthy lifestyle in your post-cancer life.

## **Health and Cancer Prevention/Screening**

All cancer survivors should have a primary care provider (PCP) who is familiar with your cancer diagnosis and treatment. See your PCP at least once a year for a physical. These visits may include cancer screening. Your care plan will outline any specific testing you should have. The following recommendations apply to all survivors.

- Vaccines are an important part of protecting yourself against illness. After cancer treatment, you may need to catch up on recommended vaccines or have booster doses. Talk with your cancer care team about what vaccines you should get and when. Share this information with your primary care provider who can administer these vaccines.
- HPV Vaccine: Human Papilloma Virus (HPV) is a virus that causes cervical, anal, and penile cancers

and certain cancers of the head and neck. Cancer survivors are at higher risk of HPV-related cancers. You should receive the 3-dose series of the HPV vaccine.

- You should participate in any cancer screening tests recommended for your age such as cervical cancer screening and mammogram for females, colon cancer screening, thyroid exam, and skin cancer screening for all survivors. You may need screening earlier than the general public depending on your family and personal health history. Talk with your cancer care team about when you should begin cancer screenings.

### Key Takeaways

- Vaccines are an important part of staying healthy. Follow your care team's recommendations for vaccines.
- The HPV vaccine reduces the risk of HPV-related cancers and is recommended for all survivors.
- Participate in cancer screenings recommended for your age and history.

## A Note on Fatigue

Some survivors report significant fatigue years after completing therapy, which can be extremely frustrating for the survivor and those around them. It is important to remember that fatigue can have many causes and, particularly if fatigue is worsening or new, it should be discussed with your healthcare team to rule out treatable causes.

While it may seem overwhelming to start exercising, many studies have shown that light to moderate exercise can combat fatigue and improve your energy level. Exercise can take many forms, from walking, biking, or swimming to more structured classes at a gym. Start slow and gradually increase the amount and intensity of your activities. Enlist a friend to be an exercising partner, who can encourage and support you on days when you can't get motivated.

### Key Takeaways

- Make sure that fatigue is not being caused by another problem. Find ways to cope and manage the fatigue. Regular exercise, acceptance, and reprioritizing will help.
- Alert your healthcare provider if fatigue is worsening or a new symptom so they can evaluate this.
- Get regular exercise to help combat fatigue.

## Well-Being After Cancer

Getting cancer as a child or teenager can have a big impact on development, goals, identity, and well-being.

## Support Groups

There are many groups and organizations that offer services for adolescent and young adult survivors. [The Psychosocial Services Resource Guide for Adolescent and Young Adult Survivors of Cancer](#) is a handbook created by CHOP that lists resources in the tri-state area.

- Many people in your life may not understand how cancer has impacted you. It may be helpful to join a



group of survivors, either formally (in a support group) or informally (connecting on social media or planned events). [CancerCare](#) provides free counseling and a variety of support groups online and by phone.

- Stupid Cancer is an organization created for young adults that provides a community of survivors to connect with. They also host the annual conference, CancerCon.

## Psychological Well-Being

After being diagnosed with cancer as a child or teenager, you may face challenges adjusting back to “normal life”. You may still have health problems or disabilities that get in the way. Returning to school or work or trying to reconnect with friends and peers can be especially difficult. When emotions become too overwhelming, it may be helpful to seek a referral for a mental health professional. You especially want to seek help if you are dealing with depression and anxiety. Signs of a serious problem can include difficulty with sleep and daytime function, hopelessness, thoughts of self-harm, recurrent bad memories or thoughts, and frequent worrying. These are indicators that professional help is needed. Some worry about health or the cancer coming back is normal, but when it interferes with living your life, it is important to get help.

Some tips:

- Ask your healthcare provider to recommend a psychological professional. Oncology social workers can also provide resources and referrals for ongoing mental health counseling.
- You can also search the [Psychology Today's Therapist Finder](#) to find practitioners in your area.
- If you are a student, your school may offer counseling and psychological services. These are usually offered as part of your tuition and fees. These counselors can be extremely helpful in navigating mental health issues for young adults while pursuing their educational goals.
- If you are working, you may want to start with your health insurance network of mental health providers or your employer's Employee Assistance Program (EAP). Mental health services are required as an essential health benefit under the Affordable Care Act for most insurance plans. Contact your plan for a list of in-network providers.
- Refer to the back of your insurance card for the number or website where you can search for mental health providers that will take your insurance.
- Text-based or online counseling is also an option. [Talkspace](#) is a text-based platform that offers various types of virtual counseling and therapy. This can be a great choice if you live in an area where therapists are not readily available.

## Schooling, Employment & Insurance

After a cancer diagnosis and treatment, you may need extra support at school or work or a different type of support than before. You may need to discuss certain accommodations or modifications to help you be successful in work or school. You should learn about your rights and your school/employer's responsibilities under the law. Cancer treatment and related costs can be expensive. Talk with your oncology social worker about what financial resources are available.

If you are attending college, it is important to register with the Office of Disabilities at your school in case any issues related to your cancer therapy arise or for help with the management of chronic health conditions while in school. Additional financial aid may also be available for students impacted by cancer.

[OncoLink's section](#) on legal, insurance, employment, and financial concerns is a good resource. LIVESTRONG Navigation Services ([online](#) or 1-855-220-7777) is a free resource that can help you find resources and address financial, employment, insurance, and coping concerns. [Cancer and Careers](#) is a resource for all things work-related, from time of diagnosis well into survivorship. [The American Cancer](#)



[Society](#) website has 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.

Other resources that might be useful include:

- Health Insurance Web Portal ([healthcare.gov](https://healthcare.gov))
- Pennsylvania Health Law Project ([www.phlp.org](https://www.phlp.org))
- American Cancer Society ([www.cancer.org](https://www.cancer.org))
- Livestrong ([livestrong.org](https://livestrong.org))
- Kaiser Family Foundation ([kff.org](https://kff.org))
- [OncoLink Insurance Education Webinars](#)

## Fertility, Sexuality & Relationships

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](#) and [Resolve](#) provide fertility information and resources for support related to fertility concerns. The [Alliance for Fertility Preservation](#) has education and a list of resources with financial assistance programs. The [American Cancer Society](#) provides fertility and sexuality resources. Your oncology team can recommend local counseling services if needed.

## Organizations for Support & Resources

The following websites and organizations offer support services and opportunities for survivors across the country, but make sure to look or ask your care team about for groups local to you as well!

### American Association for Cancer Research (AACR)

<https://www.aacr.org/patients-caregivers/patient-advocacy/>

The Survivor and Patient Advocacy Program creates partnerships among cancer survivors, patient advocates, and scientific communities. Membership applications are available for cancer survivors who wish to become survivor advocates.

### American Cancer Society: Cancer Survivors Network (CSN)

<https://csn.cancer.org/>

Provides a community of cancer survivors and families through online chats and message boards, the Cancer Survivors Network, and support groups.

### American Cancer Society: National Cancer Information Center

<https://www.cancer.org/about-us/what-we-do/providing-support.html> or 1-800-227-2345

Not sure where to find what you need? American Cancer Society's Cancer Information Services connects patients and families with all kinds of resources 24 hours a day, 7 days a week.

### American Childhood Cancer Organization

[www.acco.org](https://www.acco.org) or 1-800-366-CCCF

The American Childhood Cancer Organization provides information, support and advocacy information. This is a self-help network for parents of children with cancer. Services include support from other families, reading materials, a quarterly newsletter for parents and professionals, and a newsletter for children.

## **Bite Me Cancer**

<https://www.bitemecancer.org/>

Bite Me Cancer is an organization that was started by a 19-year old with thyroid cancer. The group distributes teen support bags to hospitals around the country.

## **BMT InfoNet's Caring Connections Program**

[www.bmtinfonet.org/services/support](http://www.bmtinfonet.org/services/support)

This program matches bone marrow transplant patients and caregivers with survivors and experienced caregivers. Sign up online.

## **Camp Make-A-Dream Young Adult Survivors Conference (YASC)**

[www.campdream.org](http://www.campdream.org) or 406-549-5987

YASC is a six-day, cost-free, medically supervised educational program in Montana designed to address issues of survivorship, provide information about being a cancer survivor, and develop lasting supportive relationships between young adult survivors. They also offer conferences and camps that target specific groups, including teens, parents, and families.

## **Cancer.net**

[www.cancer.net/patient/Survivorship](http://www.cancer.net/patient/Survivorship)

Cancer.net has survivorship resources, steps to take after cancer, information about late effects, and rehabilitation.

## **Children's Oncology Group**

[www.survivorshipguidelines.org](http://www.survivorshipguidelines.org)

The Children's Oncology Group provides guidelines and recommendations about long-term follow-up for cancer survivors. There is information available about different diagnoses, possible side effects from treatment, co-occurring conditions, finances, late effects, and emotional issues.

## **First Descents**

<https://firstdescents.org/>

First Descents provides life-changing outdoor adventures for young adults impacted by cancer and other serious health conditions.

## **Stupid Cancer**

[www.stupidcancer.org](http://www.stupidcancer.org)

Stupid Cancer is a national cancer advocacy, research, and support organization. They work to create shared experiences through live events and digital content that end isolation, build community, provide education, and foster meaningful relationships that last a lifetime. They also hold a large annual conference called CancerCon for Young Adults.

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