SMART ALACC
Adult Living After Childhood Cancer

Name:

MR#:

Your Summary

Your personalized Smart ALACC 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 have

You received the following treatments for Retinoblastoma

- Removal of the Eye (Ennucleation)
- Carboplatin (Paraplatin®)
- Etoposide (VePesid®, VP-16)
- Melphalan given into the eye (Intravitreal)
- Vincristine (Oncovin®, VCR)
- Radiation to the Eye
- Proton-based radiation

Coordinating Your Care

As a survivor, it is important that you keep a treatment summary and a copy of your care plan. You may also include your doctor’s information and current medications (Visit the OncoPilot section for forms you can use to organize this material). While some survivors continue to see an oncologist or specialized survivorship doctor, many return to a primary care provider or internist for routine care, many of whom are uncertain how to care for you. Developing the Care Plan can help you and your medical team understand what issues to look for, and how to handle them.

If you would like to find a long-term follow up clinic check out our list of clinics here (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.

What's In Your Care Plan

- Your Summary
  - Follow Up Care for Retinoblastoma
- Risks Related to Surgery
  - Removal of the Eye (Ennucleation)
- Risks Related to Medications
  - Chemotherapy in the Eye (Intravitreal)
  - Peripheral Neuropathy
  - Development of Kidney Problems
  - Hearing Changes or Loss
  - Elevated Cholesterol Levels
  - Risk of Developing Osteoporosis
  - Raynaud's Phenomenon
  - Learning Differences
  - Understanding New Research and Therapies
  - Risk of Developing a Secondary Cancer
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- Side Effects of Radiation
  - Side Effects of Radiation
  - Pediatric Partial Brain Radiation
  - Eye Health
  - Maintaining Healthy Skin
- Healthy Living After Cancer
  - Healthy Living After Cancer
  - General Cancer Screening for Women after Retinoblastoma
  - A Note on Fatigue

Follow Up Care for Retinoblastoma

After completing your treatment, you will have medical exams, eye exams and imaging (MRI scans up until age 5 years) to monitor for your cancer coming back. In general, visits occur frequently (example: every 3 months) right after the end of therapy 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 medical exams are spaced out over time. If you have not already, your healthcare team should be discussing the genetics of retinoblastoma with you, as this has been well established. You and your healthcare team should begin to discuss keeping you healthy in the long-term ("survivorship care"). Survivorship care includes all of the items discussed in this plan and may involve seeing other healthcare teams (like doctors or nurses who follow cancer survivors, primary care teams or specialists) in addition to your primary oncologist and team.

- Continue eye exams (as instructed initially and then yearly for life) with an ophthalmologist for both affected and non-affected eye and report any vision changes between exams

Risks Related to Surgery

Removal of the Eye (Ennucleation)

Removal of an eye can be emotionally difficult because of the loss of vision in one eye and the cosmetic issues that come along with having a prosthesis. Working closely with an ocularist/eye doctor at least once a year can help to make sure that your prosthesis fits well, and that you have no other vision concerns. Vocational rehabilitation can also be helpful to identify ways you can continue to participate productively in school and work.

🔑 Key Takeaways

- After surgical removal of one eye, you should be seen yearly by an eye doctor to ensure your prosthesis is fitting well and that you have no other vision concerns.

Risks Related to Medications

Chemotherapy in the Eye (Intravitreal)

Chemotherapy given into the eye can be successful in saving the eye and a survivor's vision. Studies have not found any long term side effects with this treatment, but there is not enough known to say for sure. Report any changes in vision to your provider.

Peripheral Neuropathy

Peripheral neuropathy is caused by irritation or damage to nerves, resulting in feelings of numbness, “pins and needles,” tingling, burning, or a generalized weakness/heaviness of the limbs. This toxicity can cause difficulties with fine motor skills such as buttoning a shirt, sensation of hot or cold (causing a safety hazard), or difficulty walking. In many patients, this toxicity resolves within weeks to months after completing therapy or stopping the drug that caused the problem. Unfortunately, for others, the problem becomes a chronic one, requiring physical, occupational and medical therapy as well as adaptive changes to ensure safety.

Pain management is best achieved with medications that are not typically thought of as pain medications. These include tricyclic antidepressants, gabapentin and pregabalin. If the pain is not well managed, referral to a pain specialist or physical/occupational therapist may be helpful.

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

🔑 Key Takeaways

- 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.

Development of Kidney Problems

Cisplatin, carboplatin and ifosfamide can cause damage to kidney function. This is more common in childhood cancer survivors treated under the age of 5 and the risk in adult survivors is not well understood. Risk is increased if the kidneys were in the field of radiation therapy. Kidney damage may present with elevated blood pressure or abnormalities in electrolytes (blood test). Survivors who develop high blood pressure or electrolyte abnormalities should be referred to a kidney specialist for consultation.

Key Takeaways

- Have blood pressure checked annually during physical exam
- Have electrolytes (blood chemistries) checked with physical exam.

Hearing Changes or Loss

Ototoxicity can present as hearing loss, tinnitus (ringing in the ears) or vertigo (sensation of spinning or loss of balance). This is most commonly seen in survivors treated with cisplatin or carboplatin (in high doses) as young children and those who received these medications in combination with radiation therapy to the head/neck area. Hearing loss may be seen in as many as 26% of adult survivors of testicular cancer treated with cisplatin. This finding may translate to survivors of other cancers treated with cisplatin.

Some hearing loss may go unnoticed because it affects frequencies higher than speech. Survivors should report any hearing difficulties or other signs of ototoxicity (ear problems). You should have an audiogram or consult with an audiologist if you develop any hearing or ear problems.

Key Takeaways

- Report the following symptoms to your healthcare provider, and request an audiogram and consult with audiologist:
  - Hearing loss
  - Trouble hearing the TV, or need for increased TV volume
  - Trouble hearing others in meetings or at large gatherings
    - Ringing in your ears
    - Dizziness/spinning and/or loss of balance

Elevated Cholesterol Levels

Survivors who received cisplatin and/or carboplatin may develop elevated cholesterol at earlier than expected ages. You should have fasting lipids checked with a blood test after completion of cancer therapy and annually thereafter.

Key Takeaways

- Have cholesterol checked after completing therapy and annually thereafter.

Risk of Developing Osteoporosis

Osteoporosis is a decrease in bone density (thinning of the bones) that can lead to fractures (broken bones). Long term use of corticosteroids (dexamethasone or prednisone, > 5mg per day for more than 2 months), receiving certain chemotherapy medications, and 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 removal of testicles are at greater risk. In addition, patients who have undergone gastrectomy (removal of the stomach) are at increased risk to develop osteoporosis.

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
    - If you cannot take in 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 multiple times a day. If you take Synthroid (thyroid hormone), separate it from calcium doses by at least 4 hours.
- Take 800-1000 IU of vitamin D3 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 first with your care team to determine if it is safe.
    - Start with what is comfortable for you and work up to the following recommendations:
    - Get 30-40 minutes of weight bearing exercise 3 times a week. Weight bearing exercises are those in which your feet or legs bear your body’s weight while the bones and muscles work against gravity. Examples include: walking, jogging, Tai Chi, yoga and dancing.
    - Strength training 2-3 times per week, with a day of rest in between each session. Complete 8-12 repetitions of the exercises below, and repeat them two times (2 sets). Choose a weight where the tenth repetition is hard for you to complete and you can’t complete an 11th time. Now remove 1-5 pounds from that "maximum weight," and use that as your training weight. When you can easily do 12 repetitions, try to increase the weight by 3-5lbs.
    - Exercises include: leg extensions, calf raises, leg curls, chest press, latissimus pulldown, overhead press, row machine and curl ups.
    - Your provider can refer you to a physical therapist or a physical medicine and rehabilitation physician for more guidance regarding bone-strengthening exercises.
        - Decrease or stop caffeine intake and limit alcohol intake, as these can weaken bones.
        - Quit smoking. 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 exercise 2-3 times per week.
- Calcium intake of 1000-1200mg per day plus Vitamin D 800iu to 1000iu per day (ideally from food sources, and supplements when your diet is not sufficient).
- Consider screening for osteoporosis with 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 experience the symptoms in their hands/fingers or feet/toes, but it can involve the nose, earlobes, lips or cheeks as well. 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 subsides, the tissues may appear red from the rush of blood back into them.

Survivors who have received vinca alkaloid chemotherapies (vincristine, vinblastine or vinorelbine) are at highest risk for developing this phenomenon. Raynaud's has been seen in testicular cancer survivors and is thought to be related to the use of bleomycin, cisplatin or vinblastine in those people. Symptoms may begin during, or months after treatments are completed and while some survivors have a gradual resolution of symptoms, others do not. In some cases, Raynaud's is seen along with hypertension or erectile dysfunction because of their similar pathology.

If you have this condition, you should attempt to prevent attacks by avoiding exposing the affected area to cold. Nicotine can also constrict blood vessels, so smoking should be avoided. In addition, 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, although these have their own side effects. You should also have your blood pressure checked every year.

Key Takeaways

- Avoid smoking and medications that constrict blood vessels.
- Protect affected areas from cold exposure.
- Have your blood pressure checked every year.

Learning Differences

Many survivors who have previously received or are currently undergoing chemotherapy report experiencing cognitive changes. These changes include difficulty with short term memory, multi-tasking, new learning, reading comprehension, working with numbers and a decrease in concentration ability. Medications that may cause learning differences include intrathecal methotrexate and any radiation to the brain. 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, if present. 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 medication. Survivors who may be depressed or are experiencing anxiety would benefit from consulting with a psychiatrist or psychologist 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 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. Neurocognitive testing and cognitive rehabilitation may be of use to survivors. 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.

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 ability that is affecting your day to day life.

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.

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.

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 received, radiation and/or surgery that may have affected reproductive organs, and the age at time of treatment. With all of these variables, it is sometimes difficult to predict a survivor's reproductive health. Regardless of treatments received, all women should use protection if sexually active if pregnancy is not desired, and to protect against sexually transmitted infections. Survivors who wish to assess their fertility should consider seeing a reproductive specialist who has experience working with cancer survivors. Specialists may be able to perform tests to help evaluate fertility.

Chemotherapy agents that are most strongly tied to infertility are alkylating agents (including cyclophosphamide and ifosfamide), and risks are higher with higher doses of these medications. High dose chemotherapy, used in preparation for stem cell transplant, typically results in acute ovarian failure and, in turn, infertility. Radiation to the abdomen, pelvis, brain, or full body (TBI) can also impact fertility.

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

If you are a healthcare provider reviewing the plan with your patient and would like to document the alkylator chemotherapy dose that your patient received, you may do so here:

Alkylator Dose (specify drug and dose) ________________________________

For survivors creating the plan without a healthcare provider, please discuss these factors with your team to get the best understanding of your individual risk.

🔑 Key Takeaways

- Survivors wishing to become pregnant should consider consulting with 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.

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.

Pediatric Partial Brain Radiation

Radiation to the brain can affect the brain itself as well as the eyes, ears, and skin. The effects on these organs and tissues will be different based on the part of the brain that received the radiation.

Eye Health

In many patients requiring brain or head radiation, the eyes are exposed to radiation. After eye exposure, patients are at long-term risk of developing cataracts at an early age. Survivors should report any symptoms of cataracts and have an eye exam performed by an ophthalmologist every year. 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.

Radiation exposure of the eyes can also damage the tear glands, resulting in a loss of or decrease in tear production and chronically dry eyes. An ophthalmologist can recommend artificial tears or medications to stimulate tear production. Patients with dry eyes from radiation treatment may be at increased risk for corneal infections. Any eye pain should be evaluated by a healthcare provider in a timely fashion.

Other possible effects include shrinkage or loss of the eye, corneal abrasions, and ulcers, glaucoma and damage to the optic nerve, leading to vision loss or blindness.

🔑 Key Takeaways

- Survivors who were treated with radiation to the brain or eyes should have an eye exam every year, or more frequently if symptoms are troublesome.

Maintaining Healthy Skin

Radiation can lead to permanent 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 loss of the hair 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 area treated. Blood vessels of the skin in this area may become more noticeable, although this is not harmful. If the skin feels tight or sore, regularly applying vitamin E to the skin can be helpful.

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

Key Takeaways

- You should use sunscreen 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.

Healthy Living After Cancer

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, you may have concerns related to insurance, employment, relationships, sexual functioning, fertility, and emotional issues because of your treatment - these are addressed in the Life After Cancer tab. It is also important to have a plan for who will provide your cancer-focused follow-up care (an oncologist, survivorship doctor, or primary care doctor).

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.

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 treatment (certain types of chemotherapy or radiation therapy) can increase the risk of another cancer. These are called "secondary cancers" because they develop as a result of prior treatment. The increased risk of developing another cancer may also be related to exposure to 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.

General Cancer Screening for Women after Retinoblastoma

Cancer screening tests are designed to find cancer or pre-cancerous areas before there are any symptoms and, generally, when treatments are most successful. Various organizations have developed guidelines for cancer screening with available tests. For many cancers, healthy lifestyle behaviors may decrease the risk of cancer.

Cancer prevention and screening for the general public (and all survivors, unless they are told they need additional screening) includes:

- HPV Vaccine: Human Papilloma Virus (HPV) is a virus that causes cervical, anal, and penile cancers and certain cancers of the head and neck. Therefore, all who are eligible (boys and girls) should receive the HPV vaccine.
- Sun Protection: Skin cancer is one of the most common types of cancer. Practicing sun-safety, including not tanning outside or in tanning beds, and wearing sunscreen and protective clothing, can reduce your risk of skin cancer. Of note, those with darker skin pigment are still at risk of getting skin cancer. People who have received radiation are at higher risk.
- Colon Cancer: Most men and women over the age of 50 should undergo routine screening for colon and rectal cancer. This may be done with colonoscopy (most common) or other imaging or stool tests. Testing may be appropriate for younger people with a high-risk personal or family health history. In particular, the Children’s Oncology Group recommends that all young people who have required radiation to the abdomen, pelvis, lower spine, or total body undergo colorectal cancer screening every 5 years, beginning either 5 years after radiation or at age 30, whichever is LATER. Colonoscopy is the best test for colorectal cancer, although other potential tests are mentioned in the radiation risk section of the care plan.
- Healthy Living: A healthy diet and physical activity are helpful for a number of health conditions, including cancer prevention. Avoid drinking alcohol. If you choose to drink, try to limit to 1 drink per day and do not binge drink (drinking a lot of alcohol in a short period of time).
- Not smoking! Tobacco is addictive and linked to several types of cancer (not just lung cancer). All types of tobacco and cigarettes, including electronic cigarettes, should be avoided to prevent cancer.

Cervical Cancer Screening

Cervical Cancer Screening is important and begins younger than most other cancer screening tests.

Women should begin having pap smears at age 25 (per the American Cancer Society). Screening is usually done with either a primary HPV test or a combination test for HPV and Pap (co-test). These screening tests should be done every 5 years unless you have an abnormal result and require more frequent screening. While cancer screening is done every 5 years, you should still see your provider for a well-woman checkup every year.

Breast Cancer Screening

Breast Cancer Screening is important for all women. Depending on which guidelines are followed, mammography should begin at age 40 (American Cancer Society) or 50 (the United States Preventative Task Force). Breast exams performed by a healthcare provider and/or self-breast exams may be part of a screening plan, depending on guidelines and individual risk. The Children’s Oncology Group recommends that women who have received radiation to the chest, the axillary (armpit) area, or the total body should begin breast cancer screening at age 25 OR 8 years after completing radiation, whichever is *later*. Women in this group should have screening each year with both mammogram and breast MRI. Women and girls who received chest radiation should also have a physical breast examination beginning at the time of puberty, every year until age 25, and every 6 months thereafter.

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, gardening 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

- After making sure that fatigue is not being caused by another problem, find ways to best cope and manage the fatigue. Regular exercise, acceptance, and reprioritizing will help.
- Alert your healthcare provider if fatigue is worsening or a new symptom.

Life After Cancer

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. CancerCare provides free counseling and support groups online and by phone. Stupid Cancer is an organization created for people under 40 that provides a community of survivors to connect with. No one understands this time better than someone who has been there, and this support can be very valuable.

After being diagnosed with cancer as a child or young adult, you may face challenges when returning to school or work or trying to reconnect with friends and peers. How you 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 complications of past treatment, which can affect quality of life. When emotions become too overwhelming, it may be helpful to seek a referral to a mental health professional. Signs of persistent depression and anxiety can include difficulty with sleep and daytime function, hopelessness, and thoughts of self-harm. These are indicators that professional help is needed. 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 learn more about practitioners in your geographic 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 in the context of pursuing your 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.

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 may not be readily available.

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)
http://www.aacr.org/AdvocacyPolicy/SurvivorPatientAdvocacy
615 Chestnut St. 17th Floor, Philadelphia, PA 19106
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)
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
1-800-227-2345; https://www.cancer.org/about-us/what-we-do/providing-support.html
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
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
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
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
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
Cancer.net has survivorship resources, steps to take after cancer, information about late effects, and rehabilitation.

Children’s Oncology Group
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.

Stupid Cancer

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.

Together - St. Jude Childhood Cancer Information

https://together.stjude.org/en-us/

Information about all aspects of childhood cancer treatment and survivorship. Content available in written and video format, special section for AYAs. Available in multiple languages.

Schooling, Employment & Insurance

There are many resources to help survivors, but it can take some homework to find what you need. In dealing with schooling and employment issues, you should learn about your rights and your school/employer's responsibilities under the law.

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 management of chronic health conditions while in school. Additional financial aid may also be available for students impacted by cancer.

OncoLink's section on insurance, legal, employment and financial concerns may be helpful. 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. 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.

Other resources that might be useful include:

- Health Insurance Web Portal (healthcare.gov)
- Pennsylvania Health Law Project (www.phlp.org)
- American Cancer Society (www.cancer.org)
- Livestrong (livestrong.org)
- Kaiser Family Foundation (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 can help with fertility issues. The American Cancer Society provides fertility and sexuality resources. Your oncology team can recommend local counseling services if needed. CancerCare offers free counseling services by phone and online.
