

Name:			
MR#:			

## **Your Summary**

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

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

The information in your plan is broken down by:

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

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

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

## You received the following treatments for Breast Cancer

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

## Information from your oncology office

## **Coordinating Your Care**

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

If you are being followed only by a primary care practitioner, it is a good idea to maintain a relationship with an oncologist or late effects clinic, should you need any guidance or referrals with regards to late effects. Call the cancer center where you were treated to ask if they have a survivor's clinic, or find one by

searching OncoLink's Survivorship Clinic List (though this list is not exhaustive). A survivorship clinic will review the therapies you received, discuss your risks with you, and act as a consultant to your primary care team. Your OncoLife Survivorship Care Plan includes a "Healthcare Provider Summary" (found on the right side of your results), which is an abbreviated summary of recommendations that you can give to healthcare providers for reference.

## What's In Your Care Plan

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- Autologous Stem Cell or Bone Marrow Transplant
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  - Liver Resection
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  - Laryngectomy
  - Head and Neck Surgeries
  - Removal of the Thyroid (thyroidectomy)
  - Lymph Node Removal (Dissection)
  - Surgery to Remove Female Reproductive Organs (hysterectomy, oopherectomy)
  - Splenectomy (Removal of Spleen)
  - Amputation (Removal of a Limb)
  - Lung Resection
  - Removal of the Prostate (Prostatectomy)
  - Removal of the Testicle(s) (Orchiectomy)
  - Removal of a Section of the Bowel
  - Removal of the Bladder (cystectomy, bladder resection)
  - Removal of the Kidney (Full or Partial Nephrectomy)
  - Lumpectomy
  - Whipple Procedure (pancreatectomy)
  - Surgery Involving the Brain or Spinal Cord
  - Surgery to Remove the Stomach (Gastrectomy)
  - Surgery for Rectal or Anal Cancer

- · Other Surgeries Not Listed
- Removal of the Esophagus (Esophagectomy)
- Excision or Moh's Surgery
- Retroperitoneal Lymph Node Dissection (RPLND) for Testicular Cancer
- Mastectomy

## **Follow Up Care For Brain Cancer**

#### Key Takeaways

The following are general recommendations to discuss with your oncology team:

- Physical exam and brain MRI every 2-6 months (depending on tumor type) for 2-3 years, then every 6-12 months (also determined by tumor type).
- Be sure to promptly let your team know if you experience any concerning symptoms, such as depression, vision changes, headaches, dizziness, difficulty remembering things or concentrating, feeling unbalanced or difficulty walking, any numbness or tingling.
- Discuss the possibility of seizures and whether you need anti-seizure medication. If seizures are a concern, discuss safety implications, including your ability to operate a vehicle.

## **Risks Related to Medications**

## Allogeneic Stem Cell or Bone Marrow Transplant

- During the time that you are immunocompromised, you should not see other healthcare providers, such as dentists and gynecologists, without first discussing this with your transplant team.
- Avoid things that increase your risk of cardiac and lung disease, such as smoking, sedentary lifestyle and high fat diet.
- Annual flu shot. Additional vaccination schedule as determined by your transplant team.
- Annual blood work to include:
  - Thyroid function (TSH)
  - Hormone levels (Testosterone in men, Estradiol, LH and FSH in females)
  - Consider triglyceride and lipid panel
- Annual pulmonary function tests (PFTs) for those experiencing pulmonary symptoms.
- Annual eye exam, particularly for those who had TBI.
- Evaluation of bone health
  - Osteoporosis prevention: take calcium citrate 1500mg/day and vitamin D 800 IU/day.
  - Dexa scan annually for 4 years after transplant, longer if taking chronic steroids.
  - Assess for avascular necrosis (bone death caused by poor blood supply). Symptoms include: pain in affected joint, pain occurs even at rest, poor range of motion in affected joint. May need x-rays or MRI to evaluate symptoms.
- Annual dental examination once recovered from the acute effects of transplant. Dental cleanings usually require antibiotic prophylaxis.

## **Immune Therapy**

#### Key Takeaways

• Notify your healthcare provider if you develop any new, unusual or persistent symptoms.

#### **New Skin Cancers**

#### Key Takeaways

- Inspect your skin regularly for any changes or new lesions.
- Consider dermatology visits for skin exams.

## **Lung (Pulmonary) Complications**

#### **& Key Takeaways**

- Do not smoke
- Annual health maintenance
  - Pulmonary exam (may include chest x-rays or pulmonary function tests)
  - Flu vaccine annually
  - Pneumococcal (pneumonia) vaccine
- Tell your doctor if experience any of the following symptoms
  - Cough
  - Shortness of breath
  - Wheezing
- · Consider obtaining medical clearance prior to scuba diving

## **Risk of Developing Cataracts**

#### Key Takeaways

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

## **Risk of Bladder or Urinary Tract Toxicities**

### **Q** Key Takeaways

Avoid alcohol

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

## **Risk of Developing Bladder Cancer**

#### Key Takeaways

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

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

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

## **Peripheral Neuropathy**

#### 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**

#### Key Takeaways

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

## **Hearing Changes or Loss**

#### 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 balanc

#### **Elevated Cholesterol Levels**

#### Key Takeaways

• Have cholesterol checked after completing therapy and annually thereafter.

## **Risk of Developing Osteoporosis**

#### **Key Takeaways**

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

## **Risk of Osteonecrosis (bone death)**

Report any joint or bone pain to your healthcare provider.

## Raynaud's Phenomenon

#### Key Takeaways

- Avoid smoking and medications that constrict blood vessels.
- Protect affected areas from cold exposure.
- Evaluate blood pressure annually.

## **Risk of Pulmonary Toxicity**

#### Key Takeaways

- Do not smoke.
- Pulmonary exam (may include chest x-rays or pulmonary function tests)
- Flu vaccine annually
- Pneumococcal (pneumonia) vaccine
- Tell your healthcare provider if experience any of the following symptoms: cough, shortness of breath, wheezing

## **Risk of Liver Toxicity**

#### Key Takeaways

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

## **Cardiac Risk with Targeted Therapies**

- Maintain healthy lifestyle:
  - · Avoid smoking
  - Maintain a healthy weight
  - Exercise regularly
  - Eat a well-balanced diet
- Have an annual physical exam that includes a cardiac exam.
- Survivors who develop symptoms should consider being seen in a survivorship clinic or by a cardio-oncology specialist.
- Report the following symptoms to your healthcare provider:
  - Shortness of breath (with or without exertion)
  - Difficulty breathing when lying down
  - Chest pain
  - Palpitations
  - Swelling of the arms or legs

#### **Skin Toxicities**

#### Key Takeaways

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

## **Long Term Immunosuppression**

#### Key Takeaways

- Practice good hand-washing and infection prevention.
- Report any signs of infection (fever, cough, non-healing wound or sore) to your healthcare team promptly.
- Pneumococcal (pneumonia) vaccine Annual flu vaccine.

## **Understanding Chemo-brain**

#### Key Takeaways

- There is no standard treatment for chemo brain, but cognitive rehabilitation / brain games, avoiding becoming fatigued, a healthy diet, and some medications can be helpful.
- Use reminders, whether through lists, notes or smart phone alarms, to help you stay on track.
- If you believe you are experiencing chemo brain you should consult your care provider to rule out other health issues including thyroid problems, depression and anxiety.

## **Fertility Concerns for Female Survivors**

#### Key Takeaways

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

## **Fertility and Sexuality Concerns for Male Survivors**

- Survivors wishing to become pregnant or father a child should consult with a fertility specialist familiar with cancer survivors.
- Survivors dealing with erectile dysfunction (ED) should seek the help of an urologist who

#### **Cardiac Risk**

#### Key Takeaways

- Maintain healthy lifestyle
  - Avoid smoking
  - · Maintain a healthy weight
  - Exercise regularly
  - Eat a well-balanced diet
- Have an annual physical exam that includes a cardiac exam
- Survivors who develop symptoms should consider being seen in a survivorship clinic or by a cardio-oncology specialist.
- · Report the following symptoms to your healthcare provider
  - Shortness of breath (with or without exertion)
  - Difficulty breathing when lying down
  - Chest pain
  - Palpitations
  - Swelling of the arms or legs

## **Epidermal Growth Factor Receptor (EGFR) Inhibitors**

#### Key Takeaways

- Short term side effects of these medications include paronychias and trichomegaly, which tend to resolve when the drug is discontinued.
- Long term side effects are unknown at this time and research continues.

## Risk of Cardiac (Heart) Problems Related to Cisplatin

- Maintain healthy lifestyle
  - Avoid smoking
  - Maintain a healthy weight
  - Exercise regularly
  - Eat a well-balanced diet
- Female survivors should consider a cardiac exam by a cardiologist prior to becoming pregnant
- Have an annual physical exam that includes a cardiac exam
  - Evaluate blood pressure and cholesterol levels
- Report the following symptoms to your healthcare provider
  - Shortness of breath (with or without exertion)
  - Difficulty breathing when lying down
  - Chest pain
  - Palpitations
  - Dizziness/lightheadedness
  - Swelling of the arms or legs

## **Side Effects while taking Aromatase Inhibitors**

#### **& Key Takeaways**

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

## **Side Effects While taking Tamoxifen**

#### Key Takeaways

- You may experience hot flashes and other symptoms of menopause. Let your healthcare provider know if these symptoms become troublesome.
- There is a small risk of developing endometrial cancer. Be sure to report any irregular vaginal bleeding or pelvic pain/pressure promptly.
- There is a small risk of developing blood clots (typically in the in leg or lung). Notify your healthcare provider immediately if you experience any leg pain, warmth, swelling of one leg, fever, shortness of breath that comes on you very guickly, racing heart, or chest pain.
- Discuss side effects with your oncology team, as many of these are manageable. Optimal therapy can last 5 years, so management of side effects is critical to helping you stay on therapy.

## **Sexuality Concerns for Female Survivors**

#### Key Takeaways

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

## **Vision Changes**

- It is unknown if vision changes will be permanent.
- Report any worsening vision changes promptly to your healthcare provider.

Have an eye exam by an ophthalmologist every year.

## **Hypothyroidism**

#### Key Takeaways

- Annual blood work to check TSH levels and cholesterol.
- Report any symptoms of hypothyroidism to your healthcare provider.

## **Hepatitis B Infection/Reactivation**

#### Key Takeaways

- Treatment with ofatumumab (Arzerra), obinutuzumab (Gazyva) or rituximab (Rituxan) can cause survivors to develop hepatitis B or reactivation of hepatitis B.
- Report any symptoms of hepatitis B to your healthcare provider.
- Blood tests for hepatitis B should be done 6-12 months after treatment and then annually since it is unknown how long the risk lasts.

#### **Risk of Developing a Secondary Cancer**

#### Key Takeaways

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

#### What We Do Not Know

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

## **Side Effects of Radiation**

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

## Radiation to Chest wall for breast cancer (after mastectomy)

#### Key Takeaways

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

## Radiation for breast cancer (after lumpectomy)

#### Key Takeaways

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

## **Radiation for Esophageal Cancer**

#### Key Takeaways

- Evaluation by gastroenterologist/ surgeon for difficulty swallowing.
- Yearly (at least) monitoring of weight and nutrition by primary care provider.
- Evaluation by a nutritionist for weight loss.

#### **Head & Neck Cancer Radiation**

- Scar tissue caused by radiation can lead to a number of problems, dependent on the location of the radiation. Tell your care provider if you experience changes in swallowing, muscle strength and movement, swelling or pain in the head, face or neck, or difficulty opening your mouth, even years after treatment.
- Long term side effects are often best managed when treated early.
- Physical therapy, lymphedema (swelling) specialists and cancer rehabilitation specialists can be helpful in managing these long term and late effects.

## Radioiodine Therapy (I-131)

#### Key Takeaways

- Survivors should have thyroid exam and a history and physical performed annually. A neck
  ultrasound should be done initially at 6 and 12 months after treatment and then annually for 3-5
  years or longer depending on stage and type of cancer.
- Annual blood work to check thyroid function tests should also be done by the health care provider. Bloodwork may be more frequent if on replacement medication.
- Contact your healthcare provider if you are on thyroid replacement medication and start to
  experience any changes in how you are feeling as this may be an indication that the replacement
  is not at the correct dose.

#### **Brain**

#### Key Takeaways

- Consider neurocognitive testing for memory loss, dementia, or loss of intellectual function.
- Consider physical/ occupational therapy for gait abnormalities or other areas of muscle weakness or neurologic deficit.
- Consider endocrine (hormonal) evaluation with blood testing for the symptoms such as weight gain or loss, loss of libido, and change in growth patterns.

## **Spinal cord**

## Key Takeaways

- X-ray evaluation for any new back pain, loss of bowel or bladder control, paralysis, weakness of arms or legs.
- Evaluation by a neurologist for chronic, shock-like pains in the arms/ legs.
- Evaluation by an orthopedist for any new curvature of the spine.

## **Eyes**

## **Q** Key Takeaways

• Opthalmologic evaluation every 1-5 years, or more frequently if symptoms are troublesome.

#### **Ears**

## Key Takeaways

Audiogram (hearing test) for any loss of hearing, pain, ringing in the ears, or vertigo.

## Salivary glands (Parotid)

#### Key Takeaways

- Dental cleaning every 6 months.
- Annual dental exam with X-rays.
- Further evaluation of any chronic or severe jaw pain.
- Annual fluoride treatments.
- Excellent home dental care with brushing twice daily and flossing daily.
- Nutritional evaluation if eating is difficult due to decreased saliva, decreased taste/ smell, or difficulty chewing or swallowing.

#### **Sinuses**

#### Key Takeaways

• Evaluation by an otorhinolaryngologist (ENT doctor) for chronic sinus headaches or post-nasal drip.

## Throat / Upper Airway

#### Key Takeaways

- Yearly (at least) monitoring of weight and nutrition.
- Evaluation by a nutritionist if difficulty swallowing prevents intake.
- Evaluation by an otorhinolaryngologist (ENT doctor) for difficulty breathing due to upper airway problems, hoarse voice, or new/ worsening cough.

## **Thyroid**

## Key Takeaways

- Yearly history and examination of thyroid by a physician.
- Yearly thyroid testing (TSH) if symptoms arise or if the thyroid was radiated directly, with evaluation by an endocrinologist if tests are abnormal.

## **Heart / Cardiovascular**

## Key Takeaways

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

## **Breast as part of other field**

#### Key Takeaways

- Annual breast exam by a professional regardless of age or sex.
- Particular awareness of any abnormal findings, such as lumps, masses, skin change, or nipple discharge, which should be reported to a healthcare provider.
- Yearly mammograms for women, beginning at age 25, or 8 years after radiation.
- Yearly mammograms for any female patient over 40 years.
- Yearly breast MRI for women who received radiation to the chest wall between the ages of 10 and 30.

#### Lung

#### Key Takeaways

- Annual influenza vaccine.
- Pneumococcal vaccine every 5 years.
- Tobacco avoidance/ smoking cessation.
- Chest X-ray for new cough or shortness of breath.
- Immediate evaluation of hemoptysis (coughing up blood).

## **Esophagus**

#### Key Takeaways

- Evaluation by gastroenterologist/ surgeon for difficulty swallowing.
- Yearly (at least) monitoring of weight and nutrition by primary care provider.
- Evaluation by a nutritionist for weight loss.

#### **Bone**

#### Key Takeaways

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

#### Skin

## Key Takeaways

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

#### **Stomach**

#### Key Takeaways

- Evaluation by gastroenterologist for abdominal pain, blood in vomit, or blood in stools.
- Acid-reducing medicines or medicines to coat the stomach for heartburn symptoms.

#### **Spleen**

#### Key Takeaways

- Wear medic alert bracelet noting asplenia (no functioning spleen).
- Notify your healthcare team right away if you develop a temperature greater than 100.4 ° or any signs of infection (sore throat, cough, burning with urination, ear pain, rash or shortness of breath).
- Receive annual flu vaccine as well as pneumococcal, haemophilis influenza type b (HIb), meningococcal and hepatitis vaccines (per CDC guidelines).
- When traveling outside the U.S., evaluate need for additional vaccines or antibiotics.
- See your doctor for any tick or animal bites.

#### Liver

#### Key Takeaways

- Liver function testing before and after treatment.
- Annual history/ physical exam to evaluate for liver disease.
- · Avoid alcohol.
- Further liver function testing or evaluation by gastroenterologist for signs of liver disease.

#### **Gall Bladder**

#### Key Takeaways

- · Maintain a healthy weight.
- Report any family/personal history of gall stones to your healthcare provider.
- Increased risk of developing gallstones.

#### **Bowel**

- Immediate medical evaluation for severe abdominal pain, especially if accompanied by nausea/ vomiting and constipation.
- Immediate medical evaluation for bleeding from the rectum or dark stools.
- Use of anti-diarrheals for chronic diarrhea.
- Consultation by a nutritionist for weight loss or nutritional deficits.
- Immediate medical evaluation for new bleeding or abnormal passage of urine or feces.
- Colonoscopy 10 years after radiation therapy (or at age 35, whichever is later) for screening followed by colonoscopy every 5 years.

Screening colonoscopy at age 50 for all patients.

## **Nerve damage**

#### Key Takeaways

- Consider physical/ occupational therapy for difficulty with motor skills, temperature, or loss of balance.
- Treatment with tricyclic antidepressants, carbamazepine, or neurontin for neuropathic pain.
- Referral to pain specialist if pain does not improve.

## **Kidney**

#### **& Key Takeaways**

- Annual screening for hypertension and diabetes mellitus.
- Annual basic metabolic panel and urinalysis.
- Strict control of blood pressure and blood sugar.
- Evaluation by a nephrologist if kidney disease develops.

#### **Bladder**

#### Key Takeaways

- Urinalysis for any urinary symptoms, and treatment with antibiotics if infection is shown.
- Cystoscopy (small camera to evaluate bladder) for persistent bladder pain/ bleeding.
- Immediate evaluation of any bladder/ urinary symptoms with awareness that survivor may be at increased risk of bladder cancer.
- Avoidance of alcohol and smoking.

## Male pelvis

## Key Takeaways

- Yearly sexual history by a professional.
- Medications for sexual dysfunction if survivor feels these would be helpful.
- Referral to a Urologist if medicines are not helpful for discussion of implants or pump systems.
- Physical therapy for genital or groin swelling.

#### **Testicles**

- Evaluation by an infertility specialist if pregnancy is not achieved and is desired.
- Evaluation by an endocrinologist if secondary sex characteristics are absent or change (loss of facial hair, genital changes, voice changes, erectile dysfunction).

## Female pelvis

#### Key Takeaways

- Use of personal lubricants and/ or vitamin E if vaginal area is painful, dry, or tender during intercourse.
- Use of vaginal dilators for scarring causing decrease in size of vagina.
- Treatment of vulvar pain syndromes.
- Physical therapy for swelling of genital or legs.
- Evaluation by high-risk pregnancy specialist for survivors who wish to become pregnant.
- Evaluation by an endocrinologist for hormonal abnormalities and/ or premature menopause.

## **Total Body Irradiation**

#### Key Takeaways

- · Opthalmologic evaluation yearly.
- Dental cleaning every 6 months.
- Annual dental exam with X-rays.
- Annual fluoride treatments.
- Excellent home dental care with brushing twice daily and flossing daily.
- Yearly thyroid testing with TSH level.
- Liver function testing before and after treatment, with evaluation by a gastroenterologist for abnormalities.
- Annual history/ physical exam and blood testing to evaluate for liver disease.
- Avoidance of alcohol.
- Annual screening for hypertension and diabetes mellitus.
- Annual basic metabolic panel and urinalysis, with evaluation by a nephrologist for abnormalities.
- Strict control of blood pressure and blood sugar.
- Annual influenza vaccine.
- Pnuemococcal vaccine (1 or 2 doses, depending on age and condition).
- Tobacco avoidance/ smoking cessation.
- Chest X-ray for new cough or shortness of breath.
- Immediate evaluation of hemoptysis (coughing up blood).
- Yearly mammograms beginning at age 25, or 8 years after radiation.
- Yearly mammograms for any patient over 50 years.
- Annual breast exam by a professional regardless of age.
- Diligent use of sunscreen.
- Colonoscopy 10 years after radiation therapy (or at age 35, whichever is later) for screening followed by colonoscopy every 5 years.
- Evaluation by an endocrinologist for symptoms of decreased sex hormone production.

## Lymph nodes

- Radiation increases the risk of lymphedema over surgery alone. A Certified Lymphedema Therapist should be consulted at the first sign of swelling for best outcomes.
- · Survivors should be educated about self care and to notify the healthcare team with any signs of

- infection. Instructions for survivors on risk reduction are available from the NLN.
- Radiation and/or surgery can damage nerves, which can be further aggravated by scar formation and result in neuropathic pain. Survivors with this pain may benefit from seeing a pain specialist.

# Partial Breast Irradiation with MammoSite or other radioactive implant

#### Key Takeaways

- Yearly mammograms
- Annual examination of breast tissue by breast cancer specialist.
- Consideration of physical/ occupational therapy for arm pain weakness or swelling.
- Rapid evaluation for new breast or arm swelling redness or pain especially with fever.

## **Surgery Side Effects**

## **Sentinel Node Biopsy**

#### Key Takeaways

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

## **Permanent Colostomy or Ileostomy**

## **& Key Takeaways**

- Consult an ostomy nurse for concerns with your ostomy.
- Connect with other survivors with stomas via support groups or online communities (just search for "ostomy support").

## Surgery for Ovarian, Primary Peritoneal, Fallopian Tube, Endometrial/Uterine and Cervical Cancers

- Seek help for sexual side effects, which may include pain and/or dryness during intercourse.
   Vaginal estrogen creams, vaginal dilators, and pelvic floor therapy may assist with these symptoms.
- Women who have had their cervix removed during hysterectomy should continue to have pap tests and pelvic exams, as this test can also detect vaginal tissue abnormalities.
- Notify your healthcare provider if you notice signs or symptoms suggestive of recurrence: vaginal bleeding, abdominal or pelvic pain, persistent cough, or unexplained weight loss.
- For prevention of osteoporosis:
  - Avoid smoking and excessive alcohol intake.

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

## **Surgery for Vaginal and Vulvar Cancers**

#### Key Takeaways

- Seek help for sexual side effects, which may include pain and/or dryness during intercourse.
   Vaginal estrogen creams, vaginal dilators, and pelvic floor therapy may assist with these symptoms.
- Notify your healthcare provider if you notice signs or symptoms suggestive of recurrence: vaginal bleeding, abdominal or pelvic pain, persistent cough, or unexplained weight loss.
- For prevention of osteoporosis:
  - Avoid smoking and excessive alcohol intake.
  - Perform weight bearing exercise 2-3 times per week.
  - Calcium intake of 1200-1500mg per day plus Vitamin D 400-800iu or 800-1000iu per day (either in dietary intake or supplements).
  - Consider screening with DEXA scan.

## Isolated Limb Perfusion (ILP) / Isolated Limb Infusion (ILI)

## Key Takeaways

• Consult with a cancer rehabilitation specialist, physical and/or occupational therapist for chronic limb problems.

# Surgery for Appendiceal Cancer (Removal of appendix / Appendectomy)

### Key Takeaways

• Survivors are at risk for bowel obstructions, hernia (due to cutting the abdominal muscle for surgery) and changes in bowel patterns. Radiation therapy to the abdomen and treatment with chemotherapy agents that cause motility issues (vincristine, vinorelbine, or vinblastine) can increase the risk of complications.

# Surgery for Gall Bladder Cancer (gall bladder removal / cholecystectomy)

#### **Key Takeaways**

 Survivors are at risk for bowel obstructions, hernia (due to cutting the abdominal muscle for surgery) and changes in bowel patterns. Radiation therapy to the abdomen and treatment with chemotherapy agents that cause motility issues (vincristine, vinorelbine, or vinblastine) can increase the risk of complications.

#### **Liver Resection**

#### Key Takeaways

Survivors are at risk for bleeding and liver failure, especially if cirrhosis is present as well.

## **Surgery for Mesothelioma**

#### Key Takeaways

- Report any symptoms of cough, shortness of breath or wheezing to your healthcare provider.
- Do not smoke. Talk to your healthcare team about quitting if you do. Avoid exposure to second hand smoke.
- Receive the pneumoccocal vaccine and an annual flu vaccine.

## **Surgery for Thymoma or Thymic Carcinoma**

#### Key Takeaways

- Thymomas, especially thymic carcinoma, are can reoccur, even 10–15 years following surgery. It is important to follow the recommendations of your oncologist for future follow-up.
- If you experience a persistent cough, hoarseness, difficulty breathing, chest pain, or difficulty swallowing, notify your health care provider immediately.

# Surgery for Penile Cancer (Mohs surgery/full or partial penectomy / Removal of the penis)

#### Key Takeaways

- Report any changes in the appearance of the penile and groin areas, including swelling, redness
  and rash. Report any difficulty urinating, blood in the urine or pain to your healthcare team right
  away.
- Seek counseling and support for the emotional and social concerns associated with surgery for penile cancer.

## Laryngectomy

- Address safety concerns, including: notifying local 911 and EMS that you are unable to talk, medical alert bracelet, carry something to use as an alarm to get help in an emergency, pen and paper, and working smoke detectors, as your sense of smell will be impacted.
- Practical concerns include using filters and covers to protect your stoma when showering, ensuring you are in a clean air environment, and using a humidifier.
- Work with a speech language pathologist to manage both speech and swallowing concerns.

## **Head and Neck Surgeries**

#### Key Takeaways

- Comprehensive physical exam with particular attention to the head, mouth, neck, and regional lymph nodes at least once per year. The frequency of physical exams by your healthcare provider, bloodwork and imaging studies should be determined by the oncologist based on tumor type, stage and treatment received.
- Report any signs/symptoms concerning for recurrence, including weight loss, expectorating blood, difficulty swallowing, difficulty opening the mouth, persistent sores in the mouth, or earache (especially when swallowing).
- Consult a dietician for any nutrition concerns.
- Consider seeing specialists for bothersome symptoms, including physical and occupational therapists, lymphedema therapists, speech and swallowing experts, prosthetic manufacturers, pain management specialists and orthodontic specialists.
- See a dentist twice a year and practice meticulous oral care. Your dentist may recommend frequent fluoride treatments.
- Do not smoke. Talk to your healthcare team about quitting if you do. Refrain from heavy alcohol
- Report any concerns of depression or anxiety to your healthcare provider. Consider counseling or support groups to help you cope with any concerns.
- Various therapy disciplines can help in managing the side effects of treatment, including physical and occupational therapy, speech and swallowing experts, dieticians, plastic surgeons and prosthetic manufacturers and orthotics specialists.

## Removal of the Thyroid (thyroidectomy)

## Key Takeaways

- Survivors should have thyroid exam and a history and physical performed annually. A neck
  ultrasound should be done initially at 6 and 12 months after treatment and then annually for 3-5
  years or longer depending on stage and type of cancer.
- Annual blood work to check thyroid function tests should also be done by the health care provider. Bloodwork may be more frequent if on replacement medication.
- Contact your healthcare provider if you are on thyroid replacement medication and start to
  experience any changes in how you are feeling as this may be an indication that the replacement
  is not at the correct dose.

## **Lymph Node Removal (Dissection)**

## Key Takeaways

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

# Surgery to Remove Female Reproductive Organs (hysterectomy, oopherectomy)

#### **& Key Takeaways**

- Women who have had their cervix removed during hysterectomy for cancer should continue to have pap tests and pelvic exams, as this test can also detect vaginal tissue abnormalities.
- For prevention of osteoporosis:
  - Avoid smoking and excessive alcohol intake
  - Perform weight bearing exercise 2-3 times per week
  - Calcium intake of 1200-1500mg per day plus Vitamin D 400-800iu or 800-1000iu per day (either in dietary intake or supplements)
  - Consider screening with DEXA scan

## **Splenectomy (Removal of Spleen)**

#### Key Takeaways

- Wear medic alert bracelet noting asplenia (no functioning spleen).
- Notify your healthcare team right away if you develop a temperature greater than 100.4 ° or any signs of infection (sore throat, cough, burning with urination, ear pain, rash or shortness of breath).
- Receive annual flu vaccine as well as pneumococcal, haemophilis influenza type b (HIb), meningococcal and hepatitis vaccines (per CDC guidelines).
- When traveling outside the U.S., evaluate need for additional vaccines or antibiotics.
- See your doctor for any tick or animal bites.

## **Amputation (Removal of a Limb)**

#### Key Takeaways

- Survivors require education regarding the care and maintenance of their prosthesis and limb.
- Annual physical with a healthcare provider should assess for symptoms of phantom, neuropathic and arthritic pain.

## **Lung Resection**

#### Key Takeaways

- Report any symptoms of cough, shortness of breath or wheezing to your healthcare provider.
- Do not smoke. Talk to your healthcare team about quitting if you do. Avoid exposure to second hand smoke.
- Receive the pneumoccocal vaccine and an annual flu vaccine.

## **Removal of the Prostate (Prostatectomy)**

#### Key Takeaways

• Incontinence and erectile dysfunction can persist long after prostatectomy. There are things that you can do to manage these issues. Discuss options for treatment with your healthcare team.

- Report any symptoms of difficulty passing urine, blood in the urine, or pain/burning with urination to your healthcare provider, as these may be signs of infection or stricture.
- Be aware that prostate cancer survivors may be at increased risk for osteoporosis. DEXA scan, to assess bone density, may be indicated.

## Removal of the Testicle(s) (Orchiectomy)

#### Key Takeaways

- Consider testing for hypogonadism by checking testosterone, FSH and LH levels.
- Consider evaluation by a fertility specialist for those wishing to father a child.
- Avoid smoking and excessive alcohol intake
- Perform weight bearing exercise 2-3 times per week
- Calcium intake of 1200-1500mg per day plus Vitamin D 400-800iu or 800-1000iu per day (either in dietary intake or supplements)
- Consider screening with DEXA scan

#### Removal of a Section of the Bowel

#### Key Takeaways

- Eat frequent, small meals (5 to 6 times daily)
- The diet should consist of mostly complex carbohydrates, which are whole plant foods such as fruits, vegetables, and whole grains.
- This should comprise 50 to 60% of the total daily calories.
- Include lean protein from sources such as the white meat of poultry, fish, and lean meats.
- No more than 20 to 30% of the diet should be fat. The healthiest types of fat are from plant sources such as olive oil & canola oil.
- Include 5-7 servings of fruits and vegetables per day. Canned fruit and cooked vegetable such as green beans, beets, and carrots can be eaten if fresh fruit and vegetables are not tolerated.
- Simple carbohydrates/sugars should be minimized. Examples of simple sugars are fruit juices
  and beverages and food items with sugar or high fructose corn syrup listed as one of the first 3-4
  ingredients
- · Foods should be well-chewed
- Fiber and vitamin supplementation may be indicated

## Removal of the Bladder (cystectomy, bladder resection)

- Survivors who have undergone cystectomy with any type of bladder reconstruction or with continent diversions should be followed for life by an urologist knowledgeable in these procedures and their potential complications.
- Many cystectomy procedures result in sexuality issues for both men and women. Survivors should talk to their healthcare team and consider support groups to help find ways to overcome these issues.

## Removal of the Kidney (Full or Partial Nephrectomy)

#### Key Takeaways

- Have an annual history & physical by a healthcare provider, including blood pressure check.
- Do not smoke. Seek assistance with cessation if currently smoking.
- Take measures to reduce risk of damage to the remaining kidney, including avoiding contact sports.

#### Lumpectomy

#### Key Takeaways

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

## **Whipple Procedure (pancreatectomy)**

#### Key Takeaways

- Complications regarding inadequate nutrition can result after pancreatectomy or partial pancreatectomy. Supplemental pancreatic enzymes may be helpful for survivors experiencing bloating, gas, or pale, floating stools.
- Symptoms of diabetes after pancreatectomy may require insulin injections.
- Nutrition is of utmost importance. Make sure to work with a dietician and healthcare provider to ensure proper nutrition and manage problems resulting from surgery.

## Surgery Involving the Brain or Spinal Cord

#### Key Takeaways

- Report any changes in neurological function, pain, and/or side effects from medications to your healthcare provider.
- Survivors on anti-seizure and/or steroid medication should be sure to check with a healthcare provider and/or pharmacist before beginning any new medications (prescription or over the counter), vitamins, or herbal treatments, as there may be an interaction with the new medication.

## **Surgery to Remove the Stomach (Gastrectomy)**

#### **& Key Takeaways**

• Complications regarding inadequate nutrition can result after gastrectomy, in particular Vitamin B12 deficiency. Make sure to work with dietician and healthcare provider to ensure proper

- nutrition and to help manage problems resulting from surgery.
- Medications and behavioral adjustments may help with symptoms of dumping syndrome and reflux.
- Osteoporosis prevention strategies include:
  - Avoid smoking and excessive alcohol intake
  - Perform weight bearing exercise 2-3 times per week
  - Calcium intake of 1200-1500mg per day plus Vitamin D 400-800iu or 800-1000iu per day (either in dietary intake or supplements)
  - Consider screening with DEXA scan

## **Surgery for Rectal or Anal Cancer**

#### Key Takeaways

- Eat frequent, small meals (5 to 6 times daily).
- The diet should consist of mostly complex carbohydrates, which are whole plant foods such as fruits, vegetables, and whole grains. This should comprise 50 to 60% of the total daily calories.
- Include lean protein from sources such as the white meat of poultry, fish, and lean meats.
- No more than 20 to 30% of the diet should be fat. The healthiest types of fat are from plant sources such as olive oil & canola oil.
- Include 5-7 servings of fruits and vegetables per day. Canned fruit and cooked vegetable such as green beans, beets, and carrots can be eaten if fresh fruit and vegetables are not tolerated.
- Simple carbohydrates/sugars should be minimized. Examples of simple sugars are fruit juices or beverages and food items with sugar or high fructose corn syrup listed as one of the first 3-4 ingredients.
- Foods should be well-chewed.
- Fiber and vitamin supplementation may be indicated.

## Removal of the Esophagus (Esophagectomy)

#### Key Takeaways

- Adequate nutrition is essential to maintain weight and evaluation and/or ongoing consultation with a dietician may be useful.
- Report any swallowing difficulties, weight loss or pain to your healthcare providers.
- Report feelings of abdominal discomfort, including nausea, vomiting, heartburn, gas, or diarrhea to your healthcare providers, as medications may be available to treat these symptoms.

## **Excision or Moh's Surgery**

#### Key Takeaways

• Notify your healthcare provider if you notice any changes to the area of the excision, such as swelling, redness, or a new lesion or nodule (bump).

# Retroperitoneal Lymph Node Dissection (RPLND) for Testicular Cancer

#### **& Key Takeaways**

- RPLND rarely results in long term complications, but survivors should be aware of potential
  problems that may develop. Due to the number and complexity of nerves (including the spinal
  cord) in the area of the surgery, injury to these structures is possible. This can result in pain,
  weakness or paralysis.
- In a very small number of patients, the main return blood vessel for the lower extremities (inferior vena cava) is involved with tumor, which requires surgical removal. This is very rare and can result in chronic swelling of the lower extremities. In most cases, this swelling is isolated to the feet and resolves within a few months, though it can become a chronic issue.

## Mastectomy

#### Key Takeaways

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

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

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

## **Life After Cancer**

## Tobacco



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