

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

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

## Healthcare Provider Summary

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Dear Healthcare Professional

Your patient created a survivorship care plan using the OncoLife Survivorship Care Plan at [www.OncoLife.org](http://www.OncoLife.org). This report is a summary of the long-term side effects the survivor may be at risk for and recommendations for their follow-up care. The report is generated from the treatment information entered by the patient or their healthcare provider. The summary provided is supported by cancer survivorship literature and expert opinion, but should not replace communication with the patient's oncology team. Suggested management and follow-up points are broken down according to the toxicity-causing treatment (i.e. medical therapy, surgery or radiation).

Keep in mind that survivors should continue to have screening for other cancers per the American Cancer Society guidelines and routine health maintenance as recommended by the USPTF.

### 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

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## Follow Up Care After Cancer

The oncology team should provide a monitoring plan. Typical monitoring includes:

- Periodic physical exams by a healthcare provider.

- CT scans and x-rays may be done periodically, or if symptoms arise.
- Blood work when new symptoms arise

## **Follow Up Care For Acute Lymphocytic Leukemia**

The recommended follow up care for patients with ALL includes:

- Periodic complete blood count (CBC) and bone marrow biopsy / aspirate if these results are abnormal.
- Other tests as needed, including liver function tests, cerebrospinal fluid testing and cardiac testing.
- Physical exam, every 1-2 months for the first year after completing chemotherapy, every 3 months for the second year and every 6 months thereafter.

## **Follow Up Care For Acute Myeloid Leukemia**

General recommendations for ALL follow-up care state that survivors should be monitored with:

- Have a complete blood count (CBC) checked every 1-3 months for 2 years, then every 3-6 months for up to 5 years.
- A bone marrow biopsy / aspirate is only necessary if these results are abnormal.

## **Follow Up Care For Anal Cancer**

General recommendations for follow up care include:

- History and physical examination by their physician every 3 months for two years. This visit should include a digital rectal exam, anoscopy, and evaluation of the lymph nodes in the groin area.
- CT scan of the chest, abdomen and pelvis and lab tests may be used to monitor for recurrence in higher risk disease.

## **Follow Up Care For Appendiceal Cancer**

There are no formal guidelines for follow up care; therefore, the oncology team should provide a monitoring plan. Typical monitoring includes:

- Periodic physical exams by a physician.
- Abdominal CT scan every 6 months for 3-5 years, then at the discretion of the oncology team.
- Tumor markers may be evaluated every 3-6 months if they were initially elevated at the time of diagnosis (these can include CEA, CA-125 and CA 19-9).

## **Follow Up Care For Bladder Cancer**

The recommended follow-up care for patients with bladder cancer according to the stage and grade of the cancer are as follows:

- Non invasive, low grade tumors (Ta, low grade):
  - Cystoscopy every 3 months initially, with increasing intervals as deemed appropriate.
- Early stage tumors (Ta - high grade, T1 - low and high grade):
  - Cystoscopy with urine cytology every 3-6 months for 2 years, then increasing intervals as appropriate. The physician may choose to check urinary tumor markers.
  - Consider radiology tests (CT, MRI) every 1-2 years for high-grade tumors.
- Muscle invasive tumors treated with the intent to cure:

- Laboratory testing (urine cytology, liver function, electrolytes, and creatinine) and chest x-ray every 6-12 months.
- Radiologic imaging (CT, IVP, ultrasound, etc.) of the upper urinary tracts, abdomen and pelvis every 3-6 months for 2 years, then as indicated.
- If bladder-sparing surgery: cystoscopy with cytology every 3-6 months for 2 years, then at increased intervals as deemed appropriate.
- Follow up after cystectomy:
  - Laboratory work (urine cytology, creatinine and electrolytes) every 3-6 months for 2 years, then as indicated.
  - Imaging (CT, MRI) of the chest, abdomen and pelvis every 3 to 12 months for 2 years (based on recurrence risk), then as indicated.
  - Urethral washings cytology every 6-12 months.
  - If the surgery was a partial cystectomy, follow up should also include cystoscopy every 3-6 months for 2 years, then at increasing intervals to monitor for relapse in the bladder.

## Follow Up Care For Brain Cancer

There are a number of different types of brain tumors, each with its own treatment and follow up recommendations. The following are general recommendations:

- 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).
- Assess for any neurological changes, concerning symptoms of recurrence, and depression (higher risk in this population).
- Discuss the possibility of seizures and the need for anti-seizure medication. If seizures are a concern, discuss safety implications, including their ability to operate a vehicle.

## Follow Up Care For Breast Cancer

The following are recommended for follow care after treatment for breast cancer:

- Mammogram annually for those who have had a single mastectomy or lumpectomy. Educate patients about possible symptoms of recurrences including new any changes, lumps, swelling or skin rashes to your physician.
- Be seen and examined by your oncologist every 3-6 months for 3 years, then every 6-12 months for the next two years and then annually.
- Women with an intact uterus on tamoxifen should see a gynecologist annually and notify their physician of any vaginal bleeding.
- Women taking aromatase inhibitors whose menstrual cycles have stopped should have a DEXA scan as a baseline, then periodically.
- Consider referral to genetic counseling if family or personal history includes early age at diagnosis of breast cancer (<50), triple negative disease, multiple primary cancers, or a family history of breast or ovarian cancer.
- Evidence has shown that leading an active lifestyle and maintaining a healthy weight (body mass index of 20-25), may lead to improved breast cancer outcomes.
- Any new, unusual and/or persistent symptoms should be brought to the attention of your care team.

## Follow Up Care For Cervical Cancer

After treatment for cervical cancer, the following are recommended for follow-up care by the Society for Gynecologic Oncology:

- Physical and pelvic exams every 3-6 months for 2 years, then every 6 mos – 1 year in years 2-5, and then annually after treatment.
- Annual Pap testing of cervical/vaginal tissue
- Routine labs and radiologic exams are not recommended unless patient exhibits signs of recurrence including vaginal bleeding, weight loss, abdominal pain and fatigue.
- If recurrence is suspected, CT +/- PET scan are recommended
- After radiation, patients should receive education regarding use of vaginal dilators to prevent losing vaginal elasticity and the formation of scar tissue while improving quality of life and maintaining sexual function after treatment.
- Provide education to patient regarding maintaining healthy lifestyle, smoking cessation, weight management, exercise and life after cancer.

## **Follow Up Care For Chronic Lymphocytic Leukemia (CLL)**

The guidelines for CLL follow up care depend on what therapies the patient has received and if they will continue to have treatments. The oncology team should provide follow up information for this patient.

## **Follow Up Care For Chronic Myelogenous Leukemia (CML)**

The recommendations for CML follow up care depend on what therapies the patient has received and where they are in treatment. General recommendations include:

- Patients who are taking a tyrosine kinase inhibitor will be monitored for a complete cytogenetic response at 3, 6, 12 and 18 months. Once a response is detected, BCR-ABL levels are typically measured every 3-6 months.
- Patients who have undergone allogeneic transplant are typically monitored every 3 months for 2 years, then every 6 months for 3 years.
- Any new symptom should be brought to the attention of the provider.

## **Follow Up Care For Colon Cancer**

The general guidelines recommended for follow up care for colon cancer patients are based on stage and include:

Early stage:

- Survivors should undergo colonoscopy one year after surgery.
  - If advanced adenoma is present, repeat in 1 year.
  - If no advanced adenoma, repeat in 3 years, then every 5 years.
- Any new, unusual and/or persistent symptoms should be brought to the attention of your care team.

More advanced stage:

- Be seen and examined by their physician every 3-6 months for two years, then every 6 months for a total of 5 years.
- The [tumor marker](#) CEA should be checked at these visits.
- Survivors should undergo colonoscopy one year after surgery (this should be done in 3-6 months if no colonoscopy was performed before surgery).

- If advanced adenoma is present, repeat in 1 year.
- If no advanced adenoma, repeat in 3 years, then every 5 years.
- Annual CT scan for up to 5 years after diagnosis for survivors at high risk for recurrence. Stage IV survivors will have more frequent CT scans; every 3-6 months for 2 years, then every 6-12 months for up to 3 more years.

## Follow Up Care For Endometrial (Uterine) Cancer

HCP Treatment Information:

After treatment for endometrial (uterine) cancer, the following are recommended for follow-up care:

- Physical exam, including pelvic examination, every 3-6 months for the first year after treatment.
- In subsequent years, physical examination should occur every 6 months until 5 years post treatment. In patients with low risk, stage IA/grade 1 or 2 disease this exam can occur annually in years 2-5.
- Routine labs and radiologic exams are not recommended unless patient exhibits signs of recurrence including vaginal bleeding, weight loss, abdominal pain and fatigue.
- If recurrent is suspected, CT or PET +/- CA 125 testing is indicated.
- Patients should receive education regarding [use of vaginal dilators](#) to prevent losing vaginal elasticity and the formation of scar tissue while improving quality of life and maintaining sexual function after treatment.
- Consider genetic testing in patients with uterine cancer under the age of 50 or in those with family history of cancer associated with [Lynch Syndrome](#).
- Provide education to patient regarding maintaining healthy lifestyle, smoking cessation, weight management, exercise and life after cancer.

## Follow Up Care For Esophageal Cancer

The general recommendations for follow up after treatment for esophageal cancer include:

- Physical exam every 3-6 months for 1-2 years, then every 6-12 months for years 3-5, then annually thereafter.
- Blood work when new symptoms arise or there are problems maintaining adequate nutrition.
- Endoscopy and imaging studies should be obtained as recommended by the oncologist, as these are based on stage, risk, and the cancer treatment received.

## Follow Up Care For Fallopian Tube Cancer

General recommended follow up care for patients with cancer of the fallopian tube includes:

- Oncology visit every 2-4 months for 2 years, then every 3-6 months for 3 years, then annually after 5 years. Each visit should include:
  - Physical exam with pelvic exam.
  - Ca-125 level (or other tumor marker level, if these were elevated at initial diagnosis).
  - Radiology testing (X-ray, MRI, CT or PET scan) may be done if there are concerning symptoms.

## Follow Up Care For Gall Bladder / Cholangiocarcinoma

The general recommendations for follow up care for patients with gallbladder cancer include:

- The healthcare provider may consider imaging (CT scan, MRI) every 6 months for 2 year



## Follow Up Care For Head & Neck Cancers: Tongue, Lip, Oropharynx, Nasopharynx

The following are general recommendations from the American Cancer Society for survivors of head and neck cancer:

- Physical exam every 1-3 months for year 1, then every 2-6 months for year 2, then every 4-8 months for years 3-5, then every 12 months thereafter.
- Post-treatment baseline imaging of the primary site is recommended within 6 months of completing treatment. Further imaging should be conducted if there are concerning symptoms, but is not needed routinely.
- If the neck was in the radiation treatment field, thyroid stimulating hormone (TSH) levels should be checked every 6-12 months.
- If patient experiences spinal accessory nerve palsy (SAN), neck spasms (cervical dystonia), shoulder dysfunction, or lymphedema, referral to rehab specialist.
- If challenges with speech and swallowing persist, ongoing management with speech-language pathology. These issues can arise many years after treatment due to scarring and radiation damage.
- Consider medications for pain management and spasm control associated with cervical dystonia.
- If the patient continues to smoke or use alcohol, they should be referred to a cessation or counseling program to help them quit.
- Former smokers may be eligible for lung cancer screening.
- If the mouth was in the treatment field, they should have routine dental evaluations and perform regular mouth care, including fluoride, brushing and dietary restrictions to help prevent and identify any long-term damage early.
- Referral for speech, hearing and swallowing rehabilitation and/or nutritional counseling if needed.

## Follow Up Care For Hodgkin Lymphoma

### ***Follow up after treatment, up to 5 years:***

- Physical exam every 3-6 months for 1-2 yrs, then every 6-12 months until year 3, then annually.
- Annual flu vaccine.
- Annual thyroid stimulating hormone (TSH) level if radiation field included the neck.
- Some survivors may have a CT scan within the first year after treatment. Otherwise, bloodwork and radiology studies are performed as needed, based on symptoms.

### ***Follow up after 5 years:***

There has been a considerable amount of research done in Hodgkin's lymphoma survivors and, as a result, guidelines for monitoring for late effects in these survivors have been developed. The American Cancer Society recommendations include:

- Physical exam annually. Continued follow up is important to monitor for late effects.
- Check blood pressure annually. Aggressive management of cardiovascular risk factors, such as hypertension, elevated cholesterol, and elevated triglycerides, as cardiac disease can develop at a young age.
- Annual flu vaccine.
- Patients who had a splenectomy or radiation to the spleen should be re-vaccinated with pneumococcal, meningococcal and Haemophilus influenza type b (Hib) vaccines and follow recommendations for a non-functioning spleen.

- Due to cardiac risk, provider may consider a stress test / echocardiogram every 10 years. If radiation field included the neck, consider an ultrasound of the neck veins every 10 years.
- Laboratory studies, including complete blood count and chemistry profile annually. Annual thyroid stimulating hormone (TSH) level for survivors who received radiation therapy that included the neck. Lipid (cholesterol) levels should be checked twice a year.
- Annual chest x-ray or chest CT for patients who are at increased risk for developing lung cancer due to prior therapy, including alkylating agent chemotherapy (typically Cytoxan [cyclophosphamide]), radiation to the chest, or heavy smoking.
- Breast cancer screening is recommended for women who received radiation to the chest or axilla (armpit). This includes:
  - Annual breast exam by a healthcare professional, and monthly self-breast exam.
  - Begin annual mammograms 8-10 years post therapy, or at age 40, whichever is earlier.
  - Breast MRI, in addition to the annual mammogram, for women who had chest irradiation between the ages of 10 and 30 years.

## Follow Up Care For Kidney Cancer

The recommended follow up care for patients with kidney cancer includes:

- A physical exam and blood work (comprehensive metabolic panel) every 3-6 months for 2 years, then annually for 5 years.
- Radiologic testing may include: chest and abdominal CT scan, MRI, abdominal/renal ultrasound, and chest x-ray. The test and frequency are dependent on the treatment received and the stage of the cancer.

## Follow Up Care For Liver Cancer

The recommended follow up care for patients with liver cancer includes:

- Radiologic imaging every 3-6 months for 2 years, then annually.
- Alpha fetal protein (AFP) level (if initially elevated) every 3 months for 2 years, then every 6 months.

## Follow Up Care For Lung Cancer

The follow up care recommendations for patients with lung cancer include:

- For Non-small cell lung cancer:
  - Physical exam and chest CT every 6-12 months for 2 years, then annually.
- For Small cell lung cancer:
  - Physical exam and chest CT every 3-4 months for years 1 and 2, then every 6 months for years 3 through 5, then annually thereafter.
- If the patient is a smoker, provide smoking cessation advice, pharmacotherapy and counseling referrals.
- Annual flu vaccine and vaccination for herpes zoster (shingles) and pneumococcal pneumonia.
- Any new pulmonary nodules discovered on imaging should be worked up as a potential new primary.

## Follow Up Care For Melanoma

General recommendations for follow up care of melanoma are stage dependent and include:

- All survivors should have annual skin exam by a healthcare provider for life. Regular skin and lymph node self-exams, reporting any changes to your provider.
- All survivors should receive education regarding new, unusual or persistent symptoms to report to their care team as well as [sun safety](#), [skin protection](#) and [performing skin self-exams](#).

Stages IIB-IV:

- - A complete skin exam at least once a year.
  - The patient should be educated to perform a self-skin and lymph node exam monthly.
  - History and physical exam every 3-6 months for 2 years, then every 3-12 months for 3 years, then annually.
  - In the first 3-5 years, it is reasonable to perform chest x-ray, CT or PET scan and brain MRI to screen for metastatic disease in patients with high-risk disease. Radiologic screening is not recommended after 3-5 years.

Stages IA-IIA:

- - A complete skin exam at least once a year.
  - The patient should be educated to perform a self-skin and lymph node exam monthly.
  - History and physical exam every 3-12 months for 5 years, then annually.
  - Routine radiologic imaging is not recommended in asymptomatic patients.

## Follow Up Care For Mesothelioma

There are no formal recommendations for follow up care in mesothelioma; therefore, the oncology team should provide a monitoring plan. Typical monitoring includes:

- Physical exam and chest CT scan every 3 months for 2-3 years, then every 6 months until year 5, then annually thereafter.

## Follow Up Care For Multiple Myeloma

General follow up recommendations:

- Periodic physical exam monthly during initial treatment, then every 2-3 months during maintenance and observation
- Laboratory testing:
  - Quantitative immunoglobulins & quantitation of M protein at least every 3 months.
  - Complete blood count with differential, BUN, creatinine and calcium.
  - A bone marrow biopsy and serum free light chain assay are only needed if symptoms arise.
  - Radiologic testing:
    - Annual bone survey or more often if symptoms present.
    - Other radiology tests (MRI, PET) if symptoms arise.

## Follow Up Care For Myelodysplastic Syndrome (MDS)

There are no formal guidelines for MDS follow up care, however, typical monitoring includes:

- Periodic complete blood count (CBC) and bone marrow biopsy / aspirate if these results are abnormal.

## Follow Up Care For Non-Hodgkin Lymphoma

There are some 40 different types of non-Hodgkin's lymphomas, each with its own treatment and follow up recommendations. Guidelines for follow up care recommendations based on this patient's specific tumor type.

Educate your patients to report any new, unusual and/or persistent symptoms that should be brought to the attention of the care team.

## **Follow Up Care For Non-Melanoma Skin Cancers**

The general recommended follow up care for patients with non-melanoma skin cancer include:

- Basal cell cancers:
  - Skin examination every 6-12 months for life.
  - Patient should receive education regarding sun safety, skin protection and performing skin self-exams.
- Squamous cell cancers:
  - Local, resected tumor: physical exam every 3-12 months for 2 years, then every 6-12 months for 3 years, then annually.
  - Tumor with spread to lymph node: physical exam every 1-3 months for year 1, every 2-4 months for year 2, every 4-6 months for 3 years, then every 6-12 months for life.
  - Patient should receive education regarding sun safety, skin protection and performing skin self-exams.

## **Follow Up Care For Ovarian Cancer / Primary Peritoneal Cancer**

The Society for Gynecologic Oncology recommends the following post treatment care for patients with ovarian or primary peritoneal cancer:

- Oncology visit every 2-4 months for 2 years, then every 3-6 months for 3 years, then annually after 5 years. Each visit should include:
  - Physical exam with pelvic exam.
  - Ca-125 level (or other tumor marker level, if these were elevated at initial diagnosis), with other blood work as indicated.
  - Radiology testing (X-ray, MRI, CT or PET scan) may be done if there are concerning symptoms.
  - Consider referral to genetic counseling if the patient has a family or personal history including early age at diagnosis (<50) of breast or ovarian cancer, triple negative breast cancer, multiple primary cancers, or a family history of breast or ovarian cancer.

## **Follow Up Care For Pancreatic Cancer**

The recommendations for follow up care for patients with pancreatic cancer include:

- Physical examination every 3-6 months for 2 years, then annually.
- CA19-9 blood test (tumor marker test) and CT scan may also be done every 3-6 months for 2 years and then annually.

## **Follow Up Care For Penile Cancer**

Follow up care for penile cancer depends on the stage at diagnosis and the treatment received. General recommendations for follow up care after penile cancer include:

- Exams every 3-6 months for the first 2 years, then every 6-12 months thereafter. These should include a thorough examination of the penis and groin area.
- The patient should examine their penis and groin area routinely and report any changes.
- In general, CT scans and chest x-rays are done periodically in men who had lymph node involvement, or if symptoms arise in any survivor.

## Follow Up Care For Prostate Cancer

The recommendations for follow up care for patients with prostate cancer include: Follow

- For men on active surveillance/observation:
  - PSA (prostate specific antigen) every 6 months.
  - Digital rectal exam (DRE) every 12 months, which should be taken after the PSA blood specimen, as DRE can affect the PSA result.
  - Periodic repeat biopsies to evaluate whether the tumor's aggressiveness is changing. For men on active surveillance, this is usually performed one year after the initial prostate needle biopsy, and then annually.
- For men who have been treated with surgery and/or radiation therapy, post treatment surveillance includes:
  - PSA every 6-12 months for the first 5 years, then annually.
  - Digital rectal exam (DRE) every year, which should be taken after the PSA blood specimen, as DRE can affect the PSA result.
- Survivors who have locally advanced or metastatic disease should have a physical exam and PSA every 3-6 months.

## Follow Up Care For Rectal Cancer

The general recommendations for follow up care for patients with rectal cancer include:

- History and physical examination every 3-6 months for two years, then every 6 months for a total of 5 years.
- The [tumor marker](#) CEA should be checked at these visits for survivors who had tumors that were at least stage T2 at diagnosis.
- Survivors should undergo colonoscopy one year after surgery. If no colonoscopy was performed before surgery, this should be done in 3-6 months.
  - If advanced adenoma is present, repeat in 1 year.
  - If no advanced adenoma, repeat in 3 years, then every 5 years.
- Survivors at high risk of recurrence may be followed with an annual CT scan for 3 years after diagnosis.
- If the woman has received radiation therapy, she should [use a vaginal dilator regularly](#) to prevent the vaginal tissue from losing elasticity and forming scar tissue, which can make intercourse or vaginal exams painful. This is important both for improving quality of life, and for improving the ability to follow your cancer after treatment for evidence of recurrence.

## Follow Up Care For Sarcoma

Follow up recommendations vary slightly according to the histologic diagnosis and the grade of the lesion. However, in general, these recommendations include:

- A physical exam, chest imaging and imaging of the local tumor area every 2-6 months (depending on the type of sarcoma) for the first 5 years, then annually thereafter.
- Other blood work and imaging tests are ordered based on symptoms.
- Assessment of function and referral for rehabilitative therapy when needed.

## **Follow Up Care For Stomach Cancer**

The recommendations for follow up care after stomach cancer include:

- Physical exam every 3-6 months for 1-2 years, then every 6-12 months for 3-5 years, then annually.
- Radiology and laboratory tests and endoscopy are done if concerning symptoms develop.
- Patients who have had surgical removal of the stomach need to be monitored and treated for vitamin B12 and iron deficiency.

## **Follow Up Care for Testicular Cancer**

Guidelines for specific oncology follow up care are available on the Testicular Cancer Resource Center website (TCRC). This varies based on the type of testicular cancer (seminoma versus non-seminoma), the stage of the disease, and the treatment received, but generally includes:

- Physical exam, tumor markers, abdominal CT scan and/or chest x-ray.
- Monitoring for hyperlipidemia and hypertension annually, unless more frequent monitoring and treatment indicated is indicated based on health history.
- Monitoring for metabolic syndrome, as these survivors are at higher risk.

## **Follow Up Care For Thymoma Or Thymic Carcinoma**

General recommendations for follow up care after thymoma/thymic carcinoma include:

- Periodic physical exams, which should continue for at least 10 years due to the risk of late recurrence of these cancers.
- Chest CT scan every 6 months for 2 years, then annually for 5 years for thymic carcinoma and annually for 10 years for thymoma.

## **Follow Up Care For Thyroid Cancer**

The follow up care recommendations for thyroid cancer follow up care vary slightly depending on the tumor type, stage and treatment received, but in general include:

- A physical exam (including neck examination) and TSH, thyroglobulin and antithyroglobulin antibody levels at 6 and 12 months, then annually if the patient remains disease free.
- Periodic neck ultrasound.
- Some survivors will require imaging (radioiodine or non-radioiodine), depending on their initial staging and previous imaging results.

## **Follow Up Care For Vaginal And Vulvar Cancers**

There are no formal recommendations for vaginal or vulvar cancer follow up care; however, typical monitoring includes:

- Frequent exams for the first 5 years, then every 6-12 months thereafter. These should include a pelvic

exam and Pap smear.

- CT scans and chest x-rays may be done periodically, or if symptoms arise.

## Risks Related to Medications

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### Allogeneic Stem Cell or Bone Marrow Transplant

- Avoid things that increase the 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.

### Autologous Stem Cell or Bone Marrow Transplant

The premise behind autologous transplant is the ability to use very high doses of chemotherapy to treat the cancer, while trying to protect a patient's own bone marrow. This means that survivors have received high doses of any of the chemotherapy agents used during the transplant. When reviewing the information related to each late effect, keep in mind those medications that were given during transplant (and therefore in high doses), as this will be specified when dose is relevant to the effect.

### Intravesicular Chemotherapy

Giving chemotherapy directly into the bladder (intravesicular) results in very little absorption into the rest of the body (systemic absorption). As a result, most side effects will be "local", or affecting the bladder only, though some medications may cause systemic effects such as fatigue and fever. There has not been any research into the long term effects of this type of chemotherapy, though it is unlikely to cause the same problems as giving the same medication into a vein (systemically).

### Intrathecal Chemotherapy

While researchers have looked at the effects of this therapy on children, information in adults is lacking. Children who receive intrathecal therapy are at risk for neurocognitive deficits, including memory and attention problems, learning disabilities and behavioral changes. But, their brain and spinal cord are still in development, which likely leads to these problems, making it difficult to apply this research to adult survivors. Unfortunately, this lack of knowledge leaves adult survivors with little information about their risks from intrathecal therapies. It is likely that radiation to the brain and/or spinal cord along with

intrathecal chemotherapy would increase the risk of any late effects.

## **Androgen Deprivation Therapy (ADT) for Prostate Cancer**

- Androgen Deprivation Therapy can cause sexual dysfunction, hot flashes, fatigue, loss of muscle mass, osteoporosis, central weight gain, increased risk of diabetes, hypercholesterolemia, cardiovascular events, including stroke and MI. Side effects can last for many months after treatment. Long term risk of diabetes and cardiovascular risk is unclear.
- Osteoporosis prevention through calcium & vitamin D, weight bearing and strength training exercise. Consider DEXA scan.
- Annual physical. Monitor blood pressure, Hemoglobin A1C and cholesterol.

## **Immune Therapy**

- We do not yet know the long term effects of immunotherapy medications. Many of the treatment related side effects are expected to resolve in the months after therapy.

## **New Skin Cancers**

- In studies, patients developed new skin cancers and pre-cancerous lesions when taking cobimetinib and elotuzumab. Examine skin for any suspicious lesions.

## **Lung (Pulmonary) Complications**

- Annual Pulmonary exam (may include chest x-rays or pulmonary function tests for highest risk or concerning symptoms).
- Flu vaccine annually and Pneumococcal (pneumonia) vaccine.
- Strongly encourage smoking cessation.

## **Risk of Developing Cataracts**

- Increased risk for cataracts due to certain chemotherapy agents. Assess for symptoms at annual physical exam.
- Survivors should have eye exam by an ophthalmologist every 1-2 years

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

- Risks include hemorrhagic cystitis and decreased bladder capacity. Evaluate for concerning urinary symptoms and provide appropriate follow-up with urinalysis and urology consult.
- Encourage to avoid alcohol and smoking cessation.

## **Risk of Developing Bladder Cancer**

- Encourage smoking and alcohol cessation
- Patients who also received radiation to abdomen at increased risk.
- Assess for urinary symptoms.

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



- Annual physical exam that includes a complete cardiac exam.
  - Consensus opinion suggests repeat evaluation of cardiac function between 6 and 12 months post completion of therapy for high risk individuals.
  - New or worsening symptoms should prompt further investigation with cardiac biomarkers and/or echocardiogram.
  - Monitor and manage blood pressure and cholesterol levels.
- Encourage a heart healthy lifestyle- smoking cessation, proper diet and regular exercise, etc.

## **Peripheral Neuropathy**

- Peripheral neuropathy is a side effect that develops during or shortly after treatment, but can become a chronic problem for some survivors.
- It does not develop as a late effect and if a survivor does develop symptoms suggestive of neuropathy after therapy, other causes should be investigated.
- Assess for any limitations/safety hazards due to toxicity.
- Pain management with tricyclic antidepressants, gabapentin and pregabalin. Refer to pain specialist for pain that is not well managed.

## **Development of Kidney Problems**

- Monitor blood pressure.
- Annual physical exam and check electrolytes, kidney function.

## **Hearing Changes or Loss**

- Evaluate for hearing loss as part of annual physical exam.

## **Elevated Cholesterol Levels**

- Survivors who received cisplatin and/or carboplatin may develop elevated cholesterol at earlier than expected ages. Monitor cholesterol annually and treat accordingly.

## **Risk of Developing Osteoporosis**

- Long term use of corticosteroids, receiving chemotherapy medications or radiation to weight bearing bones all increase the risk of developing osteoporosis.
- Calcium intake of 1200-1500mg per day plus Vitamin D 400-800iu or 800-1000iu per day (either in dietary intake or supplements).
- Encourage smoking cessation and minimal or no alcohol intake.
- Promote healthy lifestyle with good diet and regular exercise including weight-bearing exercise 2-3 times per week.
- Consider screening with DEXA scan.

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

- Evaluate for any pain or swelling of the joints with annual physical exam.

## **Raynaud's Phenomenon**

- Avoid prescribing vasoconstrictors.

- Monitor blood pressure annually.
- Encourage smoking cessation.

## **Risk of Pulmonary Toxicity**

- Annual Pulmonary exam (may include chest x-rays or pulmonary function tests).
  - Flu vaccine annually and Pneumococcal (pneumonia) vaccine.
- Strongly encourage smoking cessation.

## **Risk of Liver Toxicity**

- Strongly encourage to limit alcohol intake.
- Monitor LFTS (liver panel), a complete blood count with platelets, and a prothrombin time test annually while on therapy.

## **Cardiac Risk with Targeted Therapies**

- Encourage a healthy lifestyle- smoking cessation, proper diet and regular exercise, etc.
- Have an annual physical exam that includes a cardiac exam.
- Experts recommend repeat evaluation of ventricular function with echocardiogram at 12 and 18 months after initiation of Herceptin therapy in particular.
- New or worsening symptoms or hypertension should prompt further investigation with cardiac blood work and/or echocardiogram.
- Consider referral to a survivorship clinic or by a cardio-oncology specialist for evaluation of symptoms.

## **Skin Toxicities**

- Encourage good hygiene and skin care.
- Evaluate for any signs of infection or non-healing skin wounds.

## **Long Term Immunosuppression**

- Evaluate for any signs of infection or non-healing skin wounds.
- Pneumococcal (pneumonia) vaccine Annual flu vaccine.

## **Understanding Chemo-brain**

- "Chemo-brain" can include difficulty with short term memory, multi-tasking, new learning, reading comprehension, working with numbers and a decrease in concentration ability.
- Evaluate for cognitive changes and confirm that any cognitive changes are not due to a treatable cause such as hypothyroidism, depression, or anxiety.

## **Fertility Concerns for Female Survivors**

- Due to cancer treatments, survivors may have sexuality fertility issues after treatment.
- Refer to reproductive specialist, experienced in working with cancer survivors, if needed.
- Pregnant survivors should consider being followed by a high-risk obstetrician, particularly after abdominal radiation, surgery involving female reproductive organs, or if they received anthracycline chemotherapy.

- Survivors should be aware of the possibility of getting pregnant even after menstruation has stopped (due to treatments). All patients who were actively menstruating before beginning cancer treatment should use birth control during cancer treatment and for months afterwards, even if periods have stopped.

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

- Due to cancer treatments, survivors may have sexuality (ED, decreased libido) and fertility issues for months to years after treatment.
- Refer to urologist and/or reproductive specialist (experienced in working with cancer survivors) if needed.

## **Cardiac Risk**

- Encourage a healthy lifestyle- smoking cessation, proper diet and regular exercise, etc.
- Have an annual physical exam that includes a cardiac exam.
- New or worsening symptoms or hypertension should prompt further investigation with cardiac bloodwork and/or echocardiogram.
- Consider referral to a survivorship clinic or by a cardio-oncology specialist for evaluation of symptoms.

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

- Side effects of EGFR Inhibitors include paronychias (inflammation of the cuticle and nail bed) and trichomegaly (long, wavy eye lash growth), which tend to resolve when the drug is discontinued.

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

- Cisplatin has been associated with increased risk of Raynaud's phenomenon, hypertension, hypercholesterolemia and cardiac events, such as myocardial infarction and angina. Interferon has been associated with higher risk of cardiac events.
- Annual physical exam with cardiac exam, including blood pressure and cholesterol monitoring.
  - Cardiac studies (echocardiogram or MUGA) with any sign of cardiac dysfunction.
- Encourage a heart healthy lifestyle including smoking cessation, proper diet and regular exercise, etc.

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

- Adjunct aromatase inhibitor treatment can last for 5-10 years after primary therapy.
- These may cause hot flashes and other symptoms of menopause.
- Arthralgias are a common side effect and can interfere with quality of life. Encourage a discussion with the oncology team to manage any symptoms that may lead the survivor to discontinue the medication.

## **Side Effects While taking Tamoxifen**

- Adjunct tamoxifen therapy can last for 5 or more years after primary therapy.
- These may cause hot flashes and other symptoms of menopause.
- There is an increased risk of endometrial cancer and blood clots while taking this medication.
- Encourage a discussion with the oncology team to manage any symptoms that may lead the survivor

to discontinue the medication.

## Sexuality Concerns for Female Survivors

- 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, as a result of cancer therapy.
- OncoLink's article on Vaginal Dryness and Painful Intercourse provides product suggestions and tips.
- Encourage open communication with patient to help them address any sexuality issues. May also consider referring to a therapist experienced in working with cancer survivors.

## Vision Changes

- Denileukin diftitox (Ontak) may cause blurry vision or loss of color vision. It is unknown if vision changes will be permanent.
- Assess for any safety concerns due to vision changes.
- Survivors should have an eye exam by an ophthalmologist every year.

## Hypothyroidism

- Some patients who received Tositumomab (Bexxar) developed hypothyroidism while on treatment. It is unknown how long this risk lasts or if hypothyroidism will be permanent.
- Check annual TSH and cholesterol levels.
- Refer to endocrinologist if hypothyroidism is difficult to manage.
- Survivors found to have hypothyroidism may also have high cholesterol levels related to the thyroid condition. These have been found to resolve once the thyroid levels are corrected.

## Hepatitis B Infection/Reactivation

- Treatment with Ofatumumab (Arzerra), Obinutuzumab (Gazyva) or rituximab can cause survivors to develop hepatitis B or a reactivation of hepatitis B.
- It is unknown if the hepatitis B vaccine can prevent the disease or reactivation from occurring.
- Screen for hepatitis B 6-12 months after treatment and then annually since it is unknown how long the risk lasts.

## Risk of Developing a Secondary Cancer

- Certain chemotherapy agents or radiation can lead to the development of leukemia, MDS, or lymphoma. This typically occurs 4-10 years after therapy, but could occur as soon as 1-3 years after therapy (early onset is most common with etoposide or teniposide).
- Annual complete blood count with differential. Evaluate for concerning sign/symptoms.

## 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.
- Evaluate for any new or worsening symptoms that may be unexplained by other factors.

## Side Effects of Radiation

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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)**

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

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

- Evaluation by a gastroenterologist or surgeon for difficulty swallowing.
- Monitoring of weight and nutrition by primary care provider at least annually.
- Evaluation by a dietitian for weight loss.

## **Head & Neck Cancer Radiation**

- Radiation can result in the development of scar tissue months to years after treatment, which can lead to swallowing problems. Any changes in speech or swallowing should be investigated by the oncology team.
- Radiation fibrosis can cause muscles in the treatment field to have spasms, stiffness, pain, become weak, and/or become rotated and tilted to the side. Physical therapy, cancer rehabilitation, supportive devices and certain medications can be very helpful in managing these changes.
- Similarly, nerves in the area that is radiated can be damaged or impinged by scar tissue, resulting in weakness or pain in the area.
- Lymphedema of the face, chin and neck area occurs somewhat rarely. If swelling develops, early referral to a lymphedema therapist can improve outcomes.
- Trismus can occur after radiation treatment, resulting in difficulty eating, speaking or performing dental care. Jaw exercises can help to prevent or improve trismus. For some patients, jaw manipulation by a dentist or treatment by a cancer rehabilitation physician can be helpful.

- Doctors who specialize in Cancer Rehabilitation Medicine can be very helpful in treating many of these concerns.

## **Radioiodine Therapy (I-131)**

- 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**

- Consider neurocognitive testing for memory loss, dementia or loss of intellectual function.
- Consider physical and/or occupational therapy for gait abnormalities or other areas of muscle weakness or neurologic deficit.
- Consider endocrine evaluation with blood testing for hormone deficiencies for symptoms including weight gain or loss, extreme fatigue, depression, poor temperature regulation, loss of libido or change in growth patterns.

## **Spinal cord**

- Radiation can damage nerves leading to loss of strength, coordination, paralysis or bowel and bladder control. Damage to the bones can cause a reduction in height, fracture or curvature of the spine.
- X-ray evaluation for any new back pain, loss of bowel or bladder control, paralysis or weakness of arms or legs.
- Evaluation by a neurologist for chronic, shock-like pains in the arms or legs.
- Evaluation by an orthopedist for any new curvature of the spine.

## **Eyes**

- Patients are at risk for developing cataracts at an early age. Damage to the lacrimal glands can result in dry eyes, increasing the risk of corneal infections. Any eye pain should be evaluated promptly.
- Other concerns include: shrinkage or loss of the eye, corneal abrasions and ulcers, glaucoma and optic nerve damage.
- Ophthalmologic evaluation every 1-5 years, or more frequently if symptoms develop.

## **Ears**

- Damage to the ears can lead to dryness of the ear canal and fluid collection in the inner ear. This can cause dizziness, tinnitus, vertigo or hearing loss. Audiogram or consult with an audiologist if these symptoms develop.
- Patients may report a feeling of "fullness" or "clogging" in the ears. This typically improves over time.

## **Salivary glands (Parotid)**

- Patients are at risk for osteonecrosis of the jaw. Their dentist should be aware of their radiation treatments. Taste and smell changes can become permanent.
- Dental cleaning every 6 months. Annual dental exam with x-rays and fluoride treatment. Further evaluate any jaw pain or non-healing oral wound.
- Home dental care should include BID brushing and daily flossing.

## **Sinuses**

- Patients are at risk for chronic sinusitis. Symptoms include post nasal drip, nasal discharge, facial pain and headaches and should be evaluated by an otolaryngologist.

## **Throat / Upper Airway**

- Scarring or swelling can make breathing, speaking or swallowing difficult. They may have a chronic cough or hoarse voice. Any worsening of symptoms should be evaluated by an otorhinolaryngologist right away, as they can signify recurrence.
- Survivors should have weight and nutrition monitored by a primary care provider. Refer to a dietitian if there is unintentional weight loss, electrolyte imbalances or dehydration. A PEG tube may be needed if supplemental calories do not resolve these issues.

## **Thyroid**

- Although risk continues for life, peak incidence of hypo and hyperthyroidism is 2-5 years after treatment, while thyroid nodules are typically seen 10 or more years after treatment.
- Annual thyroid exam and H&P by healthcare provider to evaluate for symptoms of thyroid abnormalities.
- Annual thyroid stimulating hormone (TSH) testing if symptoms are present or if the thyroid was radiated directly.
- Referral to endocrinologist if tests are abnormal.

## **Heart / Cardiovascular**

- Survivors are at risk for early CAD, hypertension, valve abnormalities, fibrosis of cardiac tissue, heart failure and MI. The risk varies greatly depending on dose, number of fractions, shielding and combination with chemotherapy.
- Annual H&P, including blood pressure, cholesterol levels and blood sugar.
- Counseling on healthy lifestyle including exercise, tobacco cessation and healthy diet.
- High-risk survivors may benefit from an annual EKG and screening echocardiogram.

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

- Annual breast and axillary exam by a healthcare professional, regardless of age or sex.
- Annual mammograms for women over 40 or beginning at age 25 or 8 years after radiation in younger women.
- Annual breast MRI for women who received chest wall radiation between the ages of 10 and 30.

## **Lung**

- The Children's Oncology Group recommends survivors should not scuba dive without medical

- clearance by a diving medicine specialist.
- Annual influenza vaccine and pneumococcal vaccine every 5 years.
- Counseling for tobacco cessation.
- Chest X-ray for new cough or shortness of breath.
- Immediate evaluation of hemoptysis.

## Esophagus

- Evaluation by a gastroenterologist or surgeon for difficulty swallowing.
- Monitoring of weight and nutrition by primary care provider at least annually.
- Evaluation by a dietitian for weight loss.

## Bone

- Radiation can increase the risk of bone fractures. Joints in the treatment field can develop permanent stiffness, pain and arthritis.
- Rapid evaluation for fracture after trauma.
- Physical or occupational therapy and NSAIDs for arthritis.

## Skin

- Skin is more sun sensitive after radiation. Counsel to use sunscreen diligently.
- Evaluation by a wound care specialist for any non-healing ulcers.
- Skin can develop chronic swelling, wounds, changes in texture and color.

## Stomach

- Gastroenterology evaluation for chronic heartburn, abdominal pain, blood in emesis or blood in stools.
- Acid-reducing medicines to coat the stomach and reduce heartburn symptoms.

## Spleen

- Radiation to the spleen results in a non-functioning spleen (functional asplenia).
- Patients should receive annual flu vaccine as well as pneumococcal, haemophilis influenza type b (Hib), meningococcal and hepatitis vaccines.
- Counsel to seek medical attention at first sign of fever.
- Consider providing patient with "stand-by" antibiotics to be taken at first sign of a fever. Replace supply periodically to avoid expiration. Be sure they understand the need to still seek medical attention immediately despite the oral antibiotic.
- Patients require immediate attention for an animal bite due to risk of *C. canimorsus*.
- Discuss risks of parasitic infestation, particularly malaria, with some international travel. Patient should be seen for any tick bites due to Lyme risk. Exposure to ticks in Cape Cod or Nantucket Island in Massachusetts can lead to infection with Babesia.
- Patients should wear a medic-alert bracelet for notification of "functional asplenia" and can get one from the MedicAlert Foundation.

## Liver

- Liver function testing before and after cancer treatment.
- Annual H&P to evaluate for liver disease.



- Counsel to avoid alcohol.
- Refer to gastroenterologist for any abnormal liver function tests or signs of liver disease.

## **Gall Bladder**

- Increased risk of developing gallstones.

## **Bowel**

- Survivors are at risk for scarring and strictures, ulceration and bleeding, chronic diarrhea and poor absorption and fistula formation.
- Immediate medical evaluation for severe abdominal pain, bleeding from the rectum, dark stools or abnormal passage of urine or stools.
- Use anti-diarrheals for chronic diarrhea.
- Consult a dietitian for weight loss or nutritional deficits.
- Consider colonoscopy 10 years after radiation therapy (or at age 35, whichever is later) for screening, followed by colonoscopy every 5 years.

## **Nerve damage**

- Consider physical or occupational therapy for difficulty with motor skills, temperature or balance.
- Treat neuropathic pain with tricyclic antidepressants, carbamazepine, gabapentin or pregabalin.
- Refer to pain specialist if pain does not improve.

## **Kidney**

- Annual H&P including hypertension and diabetes screening.
- Annual basic metabolic panel and urinalysis.
- Strict control of blood pressure and blood sugar.
- Evaluation by nephrologist if kidney disease develops.

## **Bladder**

- 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.
- Counsel to avoid alcohol and smoking.

## **Male pelvis**

- Yearly assessment of sexual functioning.
- Medications for sexual dysfunction if survivor feels they would be helpful.
- Referral to a urologist if medicines do not help for discussion of implants or pump systems.
- Physical therapy for genital, groin or leg swelling.

## **Testicles**

- Possible physical changes to the testes include changes in the skin, hair loss and atrophy (shrinking).
- 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

- 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.
- Medicines such as tricyclic antidepressants for 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

- Ophthalmologic 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
- Pneumococcal 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 from the NLN:  
<http://www.lymphnet.org/pdfDocs/nlnriskreduction.pdf>
- 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**

- Survivors of breast cancers, particularly left-sided breast cancers, may be at increased risk of cardiac complications. Please see the description of heart/ cardiovascular late effects for more information.
- Yearly mammograms and annual examination of breast tissue by breast cancer specialist.
- Caution when surgery is considered after radiation to the chest wall or reconstructed breast.
- Consideration of physical/ occupational therapy for arm pain, weakness, or swelling.

## **Surgery Side Effects**

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### **Sentinel Node Biopsy**

- Perform thorough assessment of area at risk for lymphedema, which may include limbs, genitals and abdomen.
- Concerning signs/symptoms of lymphedema may include: full or heavy feeling, skin changes (reddened, warm, cool, dry, hard, stiff), aching/discomfort, tightness, or less movement/flexibility in nearby joints.
- Encourage preventive measures, self-assessment of changes to limbs and prompt reporting of any sign of infection.
- Referral to a Certified Lymphedema Therapist at the first sign of swelling results in the best outcomes.

### **Permanent Colostomy or Ileostomy**

- Consult an ostomy nurse for concerns with ostomy.

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

- Refer to therapist specializing in sexual health and/or cancer survivors for sexual side effects and body image concerns.
- Survivors may experience pain and/or dryness during intercourse, for which vaginal estrogen creams, vaginal dilators, and pelvic floor therapy may be helpful.
- 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 also caused by HPV.
- Risk of lymphedema is significant. Referral to a Certified Lymphedema Therapist at first sign of swelling achieves the best outcomes.
- Refer to gynecologic oncologist for any signs or symptoms suggestive of recurrence: vaginal bleeding, abdominal or pelvic pain, persistent cough, or unexplained weight loss.

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

- Refer to therapist specializing in sexual health and/or cancer survivors for sexual side effects and body image concerns.
- Survivors may experience pain and/or dryness during intercourse, for which vaginal estrogen creams,

- vaginal dilators, and pelvic floor therapy may be helpful.
- Risk of lymphedema is significant. Referral to a Certified Lymphedema Therapist at first sign of swelling achieves the best outcomes.
- Refer to gynecologic oncologist for any signs or symptoms suggestive of recurrence: vaginal bleeding, abdominal or pelvic pain, persistent cough, or unexplained weight loss.

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

- Consult with a cancer rehabilitation specialist, physical and/or occupational therapist for chronic limb problems to improve functional ability.

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

- 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.
- Consider referral to Registered Dietician and/or gastroenterologist for bowel issues (chronic diarrhea, urgency, bloating/gas) affecting quality of life.

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

- 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.
- Consider referral to Registered Dietician or gastroenterologist for bowel issues (chronic diarrhea, urgency, bloating/gas) affecting quality of life.

## **Liver Resection**

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

## **Surgery for Mesothelioma**

- Patients with post thoracotomy pain syndromes may benefit from seeing a pain specialist.
- Investigate symptoms that could indicate recurrence or new primary, including cough, shortness of breath, hoarseness, hemoptysis, weight loss, bone pain or neurologic symptoms.
- In patients who have had pneumonectomy and present with signs of infection or pneumonia, consider chest x-ray to assess integrity of bronchial stump and to look for the presence of a bronchopleural fistula.
- Pneumococcal vaccine and annual flu vaccine.
- Encourage to not smoke.

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

- Thymomas, especially thymic carcinoma, are prone to recurrence, even 10–15 years following

surgery.

- Physical Exam and chest CT annually.
- Assess for symptoms of recurrence: persistent cough, hoarseness, difficulty breathing, chest pain, or difficulty swallowing.

## **Laryngectomy**

- Safety concerns: survivors should notify EMS and 911 that they cannot speak and should wear a medic alert bracelet identifying them as a neck breather.
- The survivor's oncology team should evaluate swallowing difficulties at any time after treatment.
- A Speech Language Pathologist can evaluate speech or swallowing concerns at any time point.

## **Head and Neck Surgeries**

- Survivors should be seen for comprehensive physical exams by their oncologist, with particular attention to the head, mouth, neck, and regional lymph nodes, at least once per year.
- Refer to oncologist promptly for 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).
- Refer to a dietician for any nutrition concerns.
- Consider referral to specialists for bothersome symptoms, including physical and occupational therapists, lymphedema therapists, speech and swallowing experts, prosthetic manufacturers, pain management specialists and orthodontic specialists.

## **Removal of the Thyroid (thyroidectomy)**

- 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.

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

- Perform thorough assessment of area at risk for lymphedema, which may include limbs, genitals, abdomen or head/neck area.
- Concerning signs/symptoms of lymphedema may include: full or heavy feeling, skin changes (reddened, warm, cool, dry, hard, stiff), aching/discomfort, tightness, or less movement/flexibility in nearby joints.
- Encourage preventive measures, self-assessment of changes to limbs and prompt reporting of any sign of infection.
- Referral to a Certified Lymphedema Therapist at the first sign of swelling results in the best outcomes.

## **Surgery to Remove Female Reproductive Organs (hysterectomy, oophorectomy)**

- Women who have had their cervix removed during hysterectomy for cancer treatment should continue to have pap tests and pelvic exams, as these tests can also detect vaginal tissue abnormalities, which can also be caused by HPV.

- Refer to oncology team for signs or symptoms suggestive of recurrence, including vaginal bleeding, abdominal or pelvic pain, persistent cough, or unexplained weight loss.
- Survivors may be at increased risk for osteoporosis if they developed early menopause due to therapy or received chemotherapy. Consider DEXA scan for baseline, encourage weight bearing exercise and calcium and vitamin D supplementation.

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

- Patients should receive annual flu vaccine as well as pneumococcal, haemophilis influenza type b (Hib), meningococcal and hepatitis vaccines.
- Counsel to seek medical attention at first sign of fever.
- Consider providing patient with "stand-by" antibiotics to be taken at first sign of a fever. Replace supply periodically to avoid expiration. Be sure they understand the need to still seek medical attention immediately despite the oral antibiotic.
- Patients require immediate attention for an animal bite due to risk of *C. canimorsus*.
- Discuss risks of parasitic infestation, particularly malaria, with some international travel. Patient should be seen for any tick bites due to Lyme risk. Exposure to ticks in Cape Cod or Nantucket Island in Massachusetts can lead to infection with Babesia.
- Wear a medic-alert bracelet for notification of "functional asplenia". Patients can get one from the MedicAlert Foundation.

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

- Assess for symptoms of phantom, neuropathic and arthritic pain. Consider referral to pain specialist if pain is not well managed.
- Assess stump for signs of ill-fitting prosthetic, skin irritation, breakdown or infection. Inquire about functional status, mobility and falls, as these can be a sign of poorly fitting prosthetic.
- Assess scar on residual limb for pain, ulceration, swelling and movement in all directions (adherent scars can be a source of pain).
- Survivors should see the rehabilitation medicine physician at least once a year (more often for first 2 years) for evaluation of prosthesis and any necessary adjustments. Refer to them between visits for any concerns with prosthesis or changes in weight (as little as 5 lbs. can lead to poor fit).
- Aggressive management of arthritis and diabetes (if applicable) to prevent deterioration of remaining limb.

## **Lung Resection**

- Patients with post thoracotomy pain syndromes may benefit from seeing a pain specialist.
- Investigate symptoms that could indicate recurrence or new primary, including cough, shortness of breath, hoarseness, hemoptysis, weight loss, bone pain or neurologic symptoms.
- If patient presents with signs of infection or pneumonia, consider chest x-ray to assess integrity of bronchial stump and to look for the presence of a bronchopleural fistula.
- Pneumococcal vaccine and annual flu vaccine.

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

- Incontinence and erectile dysfunction can persist long after prostatectomy. Consider pelvic floor rehabilitation for incontinence. Refer to urologist for help in managing ED or incontinence.
- Difficulty passing urine, blood in the urine, or pain/burning with urination can be signs of infection or

stricture and require further investigation.

- Be aware that prostate cancer survivors who received androgen deprivation therapy are at increased risk for osteoporosis. Consider DEXA scan for baseline, encourage weight bearing exercise and calcium and vitamin D supplementation.

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

- Consider testing for hypogonadism by checking testosterone, FSH and LH levels.
- Consider evaluation by a fertility specialist for those wishing to father a child.
- Low testosterone can lead to osteoporosis. Risk is highest for those with bilateral orchiectomy. Consider DEXA scan for baseline, encourage weight bearing exercise and calcium and vitamin D supplementation.

## **Removal of a Section of the Bowel**

- 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.
- Consider referral to Registered Dietician for bowel issues (chronic diarrhea, urgency, bloating/gas) affecting quality of life.

## **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.
- Need for chronic catheterization can result in chronic urinary tract infections, reflux of urine into the kidneys, kidney dysfunction and hydronephrosis.
- Concerns related to continent diversion include:
  - Loss of bone density or osteoporosis, vitamin B12 deficiency, kidney stones and metabolic acidosis (managed with alkaline medications).
  - The portion of bowel continues to produce mucus, which can interfere with draining of the bladder. In addition, this mucus can cause a positive pregnancy test; so female survivors should not rely on urine pregnancy tests.
  - There is a risk of developing colon polyps or cancer in the portion of bowel used and this risk is higher than the risk of colon tumors in the general population. There are no clear recommendations on screening for these polyps or tumors, which are thought to develop 5 or more years after the surgery.
- Many cystectomy procedures result in sexuality issues for both men and women. Consider referral to a therapist with expertise in sexual health and/or cancer survivors.

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

- Risk of chronic renal insufficiency after nephrectomy is a concern. CRI should be managed aggressively to avoid irreversible damage to the remaining kidney. Partial nephrectomy appears to reduce the risk of CRI.
- Annual physical should assess that blood pressure and blood sugar are normal or well controlled on

medication.

- Kidney damage may present as a decrease in kidney function, protein in the urine or hypertension.

## **Lumpectomy**

- Risks of surgery include nerve damage and scarring which can lead to decreased range of motion, pain, difficulty with motor skills and sensation on affected side.
- Consider referral to physical therapy for decreased range of motion in the shoulder.
- Consider physical or occupational therapy for difficulty with motor skills, temperature sensation or balance.
- Treat neuropathic pain with tricyclic antidepressants, carbamazepine, gabapentin or pregabalin.
- Refer to pain specialist if pain does not improve.

## **Whipple Procedure (pancreatectomy)**

- 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**

- Refer to oncology team for any neurologic changes, seizures or concerning symptoms.
- Many survivors will be taking anti-seizure medications or steroids. Clarify with patient and oncology team who is managing the doses and monitoring of levels (if applicable) for these medications.
- Corticosteroids may affect blood sugar levels. If the survivor is taking steroids, periodic checks of blood sugar and evaluation for symptoms of hyperglycemia are recommended.

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

- Survivors will require vitamin B12 injections once or twice a month for life and may require supplemental calcium, folate and iron.
- Consultation with a Registered Dietician may be helpful to manage nutritional intake, dumping syndrome and reflux.

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

- 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.
- Consider referral to Registered Dietician for bowel issues (chronic diarrhea, urgency, bloating/gas) affecting quality of life.

## **Removal of the Esophagus (Esophagectomy)**

- Nutritional status should be monitored by a primary care physician, and a dietician should be seen in consultation by survivors who are unable to take in enough food and liquids to maintain their weight



or prevent dehydration.

- Referral to gastroenterologist or GI surgeon for any new or worsening swallowing difficulties to rule out stricture or recurrence.

## Excision or Moh's Surgery

- Perform a biopsy for recurrent cancer if there is any new swelling, nodule, lesion or enlarged lymph node in the area of the excision.

## Retroperitoneal Lymph Node Dissection (RPLND) for Testicular Cancer

- Until the early 80's, RPLND resulted in almost complete resection of the sympathetic nerves in the retroperitoneum, leading to dry or retrograde ejaculation. Nerve sparing RPLND has made this a relatively rare complication, with rates ranging from 2-10%, depending on surgical skill and experience and the extent of the disease.

## Mastectomy

- Risks of surgery include nerve damage and scarring which can lead to decreased range of motion, pain, difficulty with motor skills and sensation on affected side.
- Consider referral to physical therapy for decreased range of motion in the shoulder.
- Consider physical or occupational therapy for difficulty with motor skills, temperature sensation or balance.
- Treat neuropathic pain with tricyclic antidepressants, carbamazepine, gabapentin or pregabalin.
- Refer to pain specialist if pain does not improve.

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