

Name: _____

MR#: _____

Healthcare Provider Summary

Dear Healthcare Professional

A survivorship care plan was created by or for your patient using the OncoLifeTM Survivorship Care Plan at 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 Head & Neck: Tongue, Lip, Oropharynx, Nasopharynx

- Laryngectomy
- Cisplatin (Platinol®)
- Docetaxel (Taxotere®)
- Radiation treatment for head and neck cancers
- X-ray based radiation- IMRT

Information from your oncology office

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

The following are general recommendations for follow-up care for head and neck cancer survivors:

- 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 annually thereafter.
- Post-treatment baseline scan of primary tumor site within 6 months of completing treatment. Consider Chest CT if the patient has a history of smoking. Further imaging should be conducted when your provider feels there is a concerning symptom 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, as radiation can impair thyroid function.
- 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.
- Smoking cessation and alcohol treatment counseling as indicated.
- 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.

Surgery Side Effects

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.

Risks Related to Medications

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. Consider PT and/or OT.
- 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.

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, radiation to weight bearing bones, hormone therapy, gastrectomy and orchiectomy all increase the risk of developing osteoporosis.
- Calcium intake of 1000-1200mg per day plus Vitamin D 800iu to 1000iu per day (ideally from food sources, and supplements when diet is not sufficient).
- Encourage smoking cessation and minimal or no caffeine or alcohol intake.
- Promote healthy lifestyle with good diet and weight bearing and strength training exercise 2-3 times per week.
- Consider screening with DEXA scan.

Raynaud's Phenomenon

- Avoid prescribing vasoconstrictors.
- Monitor blood pressure annually.
- Encourage smoking cessation.

Understanding Chemo-Brain

- "Chemo-brain" can include difficulty with short term memory, multi-tasking, new learning, reading

comprehension, working with numbers and difficulty concentrating.

- Evaluate for cognitive changes and confirm that any cognitive changes are not due to a treatable cause such as hypothyroidism, depression, or anxiety.

Fertility and Sexuality Concerns for Male Survivors

- Due to cancer treatments, survivors may have sexuality (ED, dry ejaculation, 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.

Risk of Cardiac (Heart) Problems Related to Cisplatin

- Platin medications stay in the vascular system for decades after treatment. This increases the risk of arterial vascular disease. Aggressively manage any cardiac risk factors and encourage healthy lifestyle.
- Annual physical exam with cardiac exam, including blood pressure and cholesterol monitoring.
 - Cardiac studies (echocardiogram or MUGA) with any sign of cardiac dysfunction.

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 signs/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

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.

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.

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. Further evaluate any jaw pain or non-healing oral wound.
- Taste and smell changes can become permanent.
- Dental cleaning every 6 months. Annual dental exam with x-rays and fluoride treatment.
- 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. Survivors may have a chronic cough or hoarse voice. Any worsening of symptoms or changes in voice should be evaluated by an otolaryngologist 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 and continue to be followed by an RD until nutritional status is stable. 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.
- Thyroid stimulating hormone (TSH) testing every 6-12 months if the thyroid was radiated directly, or as needed if symptoms develop.
- Referral to endocrinologist if tests are abnormal.

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.

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](#).

Fatigue

Fatigue is the most common side effect of cancer treatment. What many people do not know is that this feeling of overwhelming physical, mental and emotional exhaustion can last for months to years after therapy ends. However, it is important to remember that fatigue can be caused by many things and, particularly if fatigue is worsening or new, other treatable causes should be ruled out.

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