Completion of Active Treatment: Calgary & Southern Alberta

Head and Neck Cancer

Patient





[DATE]

Re: Completion of Treatment

Dear [ARIA: Insert name]

Please accept our warmest regards for the courage you have shown in completing your cancer treatment! Finishing cancer treatment is a time of change. We want you to know that even when you finish your treatment(s), you are not alone! Help and support is available.

There are things you can start or continue to do to manage your health care and improve your well-being. The information in this letter, along with the supports, resources and suggestions in the book After Treatment: Information and Resources to Help You Set Priorities and Take Action, can help prepare you to move forward and live the very best you can after your treatment(s).

Follow-up Appointments and Tests

During the early stages of your follow-up, the Primary Oncology Team (team that was most responsible for your treatment) will coordinate the follow up appointments and testing. The primary oncology team may call upon your primary care provider (family doctor) to assist with certain parts of your follow-up. Your oncology team will:

- arrange to see you on a regular basis to address any cancer-related concerns and perform focused physical exams (to ensure no signs of cancer recurrence)
- arrange tests to check for the possible return of cancer (sometimes called surveillance)
- refer you to other specialists or your primary doctor if they have any concerns that fall outside their areas of expertise

For your Head and Neck cancer follow-up:

- We recommend a physical exam with your primary oncology team. This should include a
 check of your mouth or any area that received treatment. Your follow-up may also include
 other tests or procedures such as blood tests, x-rays, screening for other cancers and
 vaccinations.
- Your cancer doctor or surgeon will recommend how often you should be seen for a follow-up and will help arrange any tests you may require.
- If your family doctor is performing some of these exams and has any concerns of possible recurrent Head & Neck cancer, he/she will refer you back to your Head and Neck cancer surgeon and/or oncologist.

Continue to See Your Primary Health Care Provider

Continue to see your primary health care provider (such as your family doctor or nurse practitioner) for your regular health exams. We will send them a summary of your cancer treatment and follow-up recommendations so they are aware of what to do for follow-up.

It is your responsibility to book your follow-up visits with your primary care provider.

If you need a family doctor, there are several ways to get connected with one:

- Ask family and/or friends if they have a family doctor that may consider accepting you as a
 patient
- Call Health Link Alberta (811)
- Go to: albertafindadoctor.ca/

Once you have a doctor, let them know they can view the guideline of health care provider follow-up recommendations at www.ahs.ca/guru.

Manage Side Effects from Treatment

Most side effects will get better over the next several months, but we do know that some side effects can linger for months or years. It is important to let your care team know about any side effects or emotional concerns so they can help you. The <u>After Treatment</u> book has suggestions for managing common side effects. If you need more information, ask your Cancer Centre or find side effect management resources at <u>www.cancercarealberta.ca</u> > Patients and Families > In Treatment.

Treatment side effects	Possible causes	What you can do
Difficulty or painful	Radiation	Treatment can cause problems with eating, drinking, and
swallowing	Surgery	swallowing.
		This should improve in the first three months after treatment
		finishes.
		If difficult and painful swallowing continues, tell your primary
		care/family doctor.
		Your doctor can refer you to a local speech language pathologist,
		or to the speech language pathologist associated with the regional
		cancer centre, so you can have an assessment and treatment.
Lymphedema (swelling	Surgery	Neck swelling may occur weeks or months after finishing treatment.
of skin/soft tissues that	Radiation	Neck discomfort can be an early symptom of lymphedema. It
does not go away)		sometimes happens with swelling, but not always.
		Ask for a referral to physical therapy or a rehabilitation oncology
		clinic.
Dry mouth (xerostomia)	Surgery	Symptoms of dry mouth and taste changes start to get better a few
	Radiation	weeks after radiation ends, but can take up to a year or more to
		recover.

Treatment side effects	Possible causes	What you can do
Wound breakdown/	Surgon	 If your dry mouth is not improving, or if your symptoms get worse, talk with your primary health care provider. It is important to brush and floss your teeth often and have regular visits with your dentist. You can buy artificial saliva and other products to help with dry mouth (such as Biotene®) at your local drug store or pharmacy.
Infection	Surgery Radiation	 Patients can experience poor wound healing in the early stages after treatment is completed. Signs of this include separation of the skin incisions, drainage from the wound (either skin or mouth), swelling, or redness. Patients should seek urgent attention of the primary oncology team/head and neck surgeon for assessment and treatment by calling the Calgary nurse coordinator at 587-231-4365.
Dry nose / sinus congestion	Radiation	 Nasal irrigation (salt water rinse) is available at pharmacies and may help with dryness and congestion after radiation. If you are experiencing these symptoms after treatment, check with your doctor to see if irrigations are recommended for you.
Neck stiffness (fibrosis)	Radiation Surgery	 Neck stiffness, discomfort and changes to your range of motion may develop and linger for months to years after radiation and surgery. Ask for a referral to physical therapy or other rehabilitation clinic.
Jaw stiffness (fibrosis)	Radiation Surgery	 Jaw stiffness, difficulty opening your mouth and discomfort may develop months to years after radiation and surgery. Ask for a referral to physical therapy or other rehabilitation clinic.
Skin color changes	Radiation	If you develop a skin reaction (redness, skin breakdown) during radiation, it should heal within a few weeks. In the long term, your skin color may change and be somewhat lighter or darker in the area that received radiation; ask your radiation oncologist if you are concerned.
Jawbone problems (osteoradionecrosis / ORN)	Radiation	 While it is rare, radiation can cause the jawbone to decay or die. If you have new pain or notice drainage or discharge in your mouth, tell your doctor or your dentist right away. They will need to arrange tests and follow-up care. Sometimes, treatment for this problem may involve surgery.
Shoulder problems	Surgery	 Shoulder problems can happen after surgery. It takes the body a long time to heal (months to years). Ask for a referral to physical therapy or other rehabilitation clinic.
Hearing loss	Chemotherapy Radiation	 Long-term hearing damage can happen because of treatment. Tell your primary care provider if you are having problems hearing. They may refer you to a specialist if you have treatment-related hearing loss.
Emotional and mental distress	Stress of cancer treatment Adjusting after treatment	Cancer treatment brings up many feelings for people. If you are struggling with feelings of helplessness, hopelessness, distress, anxiety or depression, talk to your doctor.

Treatment side effects	Possible causes	What you can do
		You can also find ideas for how to manage these feelings in the After Treatment book.
Fatigue / low energy levels	Effects of surgery and/or radiation Low thyroid hormone levels Sleep apnea	Cancer treatment may cause long-term fatigue or low energy. If you are struggling with managing your energy levels talk to your doctor.
Trouble breathing while sleeping (sleep apnea)	Effects of surgery and/or radiation	 Sleep apnea occurs when people have trouble breathing while they are sleeping. Many of the changes to your upper airway that have occurred during cancer treatment may increase the risk of sleep apnea. Sleep apnea often presents as fatigue during the day despite trying to get adequate levels of sleep. If you are struggling with this, please talk to your doctor who may order a sleep study or provide counselling and other interventions.
Thyroid problems	Radiation	 Radiation may cause your thyroid gland to malfunction months or years after treatment. If this happens, you may experience loss of appetite, weight change, intolerance to hot or cold, fatigue, constipation, or memory problems. Your primary care doctor will check your thyroid function annually after radiation. They will prescribe thyroid medication if you need it.
Weight loss	Surgery Radiation Depression following cancer	Inform your doctor if you are experiencing unplanned weight loss. You may require follow-up and referral to a registered dietitian.

Know the Signs and Symptoms of Head and Neck Recurrence

Review the list of general symptoms to watch for in the <u>After Treatment</u> book. Below are some symptoms specific to Head and Neck cancer. If these symptoms start and do not go away, call your primary care provider right away. Your provider may do tests to see if the cancer has come back or refer you back to the Cancer Centre.

- New lesion, ulcer or lump in the mouth, throat or neck
- New ear pain or throat/neck pain
- A new or enlarging lymph node(s), especially in your neck, arm pit or groin area
- New persistent cough or shortness of breath
- Unplanned weight loss

Support and General Recommendations

As you move forward, you may have questions about what is next, what you should do to take care of yourself, or how to improve your well-being. We hope that along with your care team, the After Treatment book will help you during this time of change, answer your questions, and give you the information and supports you need.

Recommended Resources:

- After Treatment: Information and Resources to Help You Set Priorities and Take Action (book)
 - the oncology care team will give you this book at the end of your treatment
 - o www.cancercarealberta.ca > Patients and Families > After Treatment
- Newly Diagnosed (book) has information on resources to help
 - www.cancercarealberta.ca > Patients and Families > Just Diagnosed > Newly Diagnosed with Cancer
- Cancer Care Alberta: www.cancercarealberta.ca

Counselling and Support:

Many patients find counselling services or support groups helpful when adjusting to life after cancer. They can help with things such as communication, stress management, coping with treatment side effects, mood changes, quality of life, body image, sexual health, or loneliness. If you would like to set up a counselling appointment, please pick the closest location from the list below and call to make an appointment:

Calgary: 587-231-3570Lethbridge: 403-388-6814Medicine Hat: 403-529-8817

For other communities, please visit <u>www.ahs.ca/cpn</u> and select "Provincial Patient Navigation"

Wellspring: The head and neck patient support group for Calgary resides within Wellspring. Patients who are either going through treatment or who have completed treatment meet regularly. Wellspring is a community-based support centre offering programs and services to help with the emotional, practical, social and restorative needs of people living with cancer and their caregivers. Programs are free of charge and you do not need a referral. To contact Wellspring Calgary, please visit https://wellspringalberta.ca.

Head and Neck Cancer Support Society: The Head and Neck Cancer Support Society is a registered society in Alberta and their purpose is to inform, assist and advocate for people living with head and neck cancer. For more information, please visit www.Head-Way.org.

Healthy Lifestyle Recommendations

You will find recommendations and information on ways to improve your well-being in the <u>After Treatment</u> book. For example, being active and exercising regularly can help with fatigue, sleep, and stress. For more information, please visit:

- Thrive Health: evidence-based exercise resources
- Alberta Cancer Exercise Program

- MyHealth.Alberta.ca: Exercise for People with Cancer
- Wellspring Alberta

Specific Concerns for Head and Neck Cancer Patients

Self-image: Please talk to your doctor if you have concerns relating to your body image following surgery. For many patients, the head and neck area is an important part of their self-image. Psychological counselling may be helpful for improving body image satisfaction, addressing relationship concerns and reducing sexual dysfunction.

Reconstruction and Rehabilitation: The contact information below may be helpful if you are considering reconstructive or rehabilitative surgery:

- Foothills Medical Centre Dental Clinic (Calgary): 587-231-5676
- Otolaryngology Head & Neck Surgery (OHN) Coordinator (Calgary): 587-231-4365

Smoking increases the chance of many cancers, you should try to quit if you smoke. Visit <u>albertaquits.ca</u> to learn more.

Sexual Health Concerns: Treatment for cancer can impact your sexual function, health, relationships, and sometimes causes distress over body image. Strategies and support are also available to help you and your partner with intimacy problems, distress, and adjusting to these changes. See the Counselling and Support numbers listed in the section above or contact the **Oncology and Sexuality, Intimacy, and Survivorship (OASIS) program** at 780-391-7664.

Ongoing Care

If there are any concerns about your cancer returning, your family doctor will refer you back to us.

Sincerely,

The Provincial Head and Neck Care Team