Guideline Resource Unit guru@ahs.ca

Transfer of Care Letter

Head and Neck Cancer

Patient



https://www.albertahealthservices.ca/info/cancerguidelines.aspx

[DATE]

Re: Transfer of Care

Dear [ARIA: Insert name]

You have finished your treatment and follow-up for Head and Neck cancer at the Cancer Centre. Please accept our warmest regards for the courage you have shown! Finishing cancer treatment is a time of change. We want you to know that even when you finish your treatment(s) and are no longer being seen at the cancer center regularly, 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 <u>After Treatment:</u> <u>Information and Resources to Help You Set Priorities and Take Action</u>, can help prepare you to move forward and live your best.

Follow-up Appointments and Tests

Since we feel you are doing well, we will use a **Primary Care** model for your follow-up. This means that your primary health care provider (family doctor or nurse practitioner) can safely do your Head and Neck cancer follow-up from now on. Your primary health care provider will:

- arrange tests to check for cancer (sometimes called surveillance)
- continue to see you for any health conditions you have or any new problems
- refer you back to a specialist or your cancer doctor (surgeon or oncologist) if they have any concerns

For your Head and Neck cancer follow-up:

- We recommend a **physical exam with your family doctor or nurse practitioner**. This should include a check of your mouth. This 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 have these tests.
- During the first five years after completing treatment, you should be seen every six months by your family doctor for a physical exam. If your family doctor 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.

Remember, it is your responsibility to book your follow-up visits with your primary care provider so they can arrange the tests you need.

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.

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If you need a family doctor, you can find one by calling Health Link Alberta (811) or going to: <u>https://www.albertahealthservices.ca/info/Page13253.aspx</u>. Once you have a doctor, let them know they can view the guideline of health care provider follow-up recommendations at <u>www.ahs.ca/guru</u>.

Manage Side Effects from Treatment

Most side effects will get better over the next several months, but 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, your Cancer Centre has detailed patient education materials for many different side effects.

Treatment side effects	Possible causes	What you can do	
Difficulty or painful swallowing	RadiationSurgery	 Treatment can cause problems with eating, drinking, and swallowing. This should improve in the first 3 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 of skin/soft tissues that does not go away)	SurgeryRadiation	 Neck discomfort can be an early symptom of lymphedema. It sometimes happens with swelling, but not always. Ask for a referral to physical therapy or a rehabilitation oncology clinic. 	
Dry mouth (xerostomia)	SurgeryRadiation	 Symptoms of dry mouth and taste changes start to get better a few weeks after radiation ends, but can take up to a year or more. 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 pharmacy. 	
Neck stiffness (fibrosis)	RadiationSurgery	 Neck stiffness, discomfort and changes to your range of motion may develop months to years after radiation and surgery. Ask for a referral to physical therapy or other rehabilitation clinic. 	
Jaw stiffness (fibrosis)	RadiationSurgery	 Jaw stiffness, restricted range of motion and discomfort may develop months to years after radiation and surgery. Ask for a referral to physical therapy or other rehabilitation clinic. 	

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Skin color changes	Radiation	 In the places you had radiation treatment, your skin may have patches of pink or red; ask for a referral to a dermatologist if you are concerned.
Jaw bone problems (osteoradial necrosis)	Radiation	 While it is rare, radiation can cause the jaw bone to decay or die. If you have pain or notice drainage or discharge in your mouth, tell your doctor 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	ChemotherapyRadiation	 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. You can also find ideas for how to manage these feelings in the <u>After Treatment</u> 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	 Your thyroid gland may not work as well as before and may not produce the right amount of hormones. If this happens, you may experience loss of appetite, weight change, intolerance to hot or cold, fatigue, constipation, or memory problems. Your doctor will check your thyroid function during your follow-up visits. They will prescribe thyroid medication if you need it.
Weight loss	SurgeryRadiation	 Inform your doctor if you are experiencing unplanned weight loss for appropriate 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. They 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 <u>After Treatment</u> book will help you during this time of change, answer your questions, and give you the information and supports you need.

Recommended Resources:

• <u>After Treatment: Information and Resources to Help You Set Priorities and Take Action</u> (book) — the oncology care team will give you this book at the end of your treatment

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: 587-231-3570	Lethbridge: 403-388-6814	Other Communities visit
Edmonton: 780-643-4303	Medicine Hat: 403-529-8817	www.ahs.ca/cpn and click:
Grande Prairie: 825-412-4200	Red Deer: 403-343-4485	Provincial Cancer Patient
Grande Fraine: 023-412-4200		Navigation

Wellspring: 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.

- <u>https://wellspringalberta.ca/</u>; 1-866-682-3135 (Toll free)

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 <u>www.Head-Way.org</u>.

Healthy Lifestyle Recommendations

You will find recommendations and information on ways to improve your well-being in the <u>After Treatment</u> book.

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.

- Reconstruction & Rehabilitation: (iRSM) Institute for Reconstructive Medicine: 780-735-2660
- Foothills Medical Centre Dental Clinic (Calgary): 587-231-5676
- University of Alberta Dental Clinic (Edmonton): 780-407-6854
- Otolaryngology Head & Neck Surgery (OHN) Coordinator (Calgary): 587-231-4365
- Otolaryngology Head & Neck Surgery (OHN) Coordinator (Edmonton): 780-407-7052

Smoking increases the chance of many cancers, you should try to quit if you smoke.

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