

HPV-Positive Oropharyngeal Squamous Cell Cancer

What you need to know

In this booklet you will learn about:

- Human Papillomavirus (HPV)
- Types of HPV
- How people get HPV
- HPV and oropharyngeal squamous cell cancer
- How oropharyngeal cancer is treated
- Support for people with oropharyngeal cancer

Table of Contents

Information on the Human Papillomavirus (HPV).....	2
Information for Family Members/Partners	4
Information on HPV-positive Oropharyngeal Squamous Cell Cancer (OPSCC).....	6
Information on Treatment and Prognosis of HPV-positive Oropharyngeal Squamous Cell Cancer (OPSCC).....	8
Information on Support and Rehabilitation Programs at the Odette Cancer Centre	10
Notes	12

Information on the Human Papillomavirus (HPV)

What is HPV?

- HPV is a very common sexually transmitted virus that can infect the oropharynx (tonsils and throat), anus and genitals.
- Most people with HPV do not have any symptoms and do not need any treatment.

Can HPV be cured?

- At this time, there is no cure for the HPV infection.
- In most cases (98-99%), the body's immune system gets rid of HPV without any treatment.

Are there different types of HPV?

- There are many types of HPV. Low-risk and high-risk types can cause warts but high-risk types can also lead to different types of cancer.
- Oral HPV infections are less common than genital HPV infections.
- Oral HPV infections are more common among men than women.
- Oral HPV infections can lead to a head and neck cancer in the oropharynx called HPV-positive Oropharyngeal Squamous Cell Cancer (OPSCC).

How might I have gotten an HPV infection?

- HPV is spread through sexual contact. This can happen when skin or mucosa (the inner lining of an organ or body part) comes in contact with an infected person's skin or mucosa during vaginal, anal, or oral sex with someone who has the virus.
- HPV can be passed to a newborn if the mother is infected.
- Symptoms of HPV may start years or even decades after having sex with someone who is infected so it is impossible to know who gave the infection to who or when the infection occurred.

Information for Family Members/Partners

Am I contagious? Can I give an oral HPV infection to others?

- HPV is not spread through casual physical contact, such as touching, sharing drinks or kissing on the cheek or lips.
- **Spouses/Long-term partners:**
 - Since HPV is sexually transmitted, it is likely that your sexual partners have HPV.
 - You and your spouse/partner do not need to make any changes in your sexual practices.

What should my partner(s) do?

- If your partner has a cervix, they should follow cervical cancer screening guidelines. In Ontario, this is a Pap test every three years if sexually active.
- There are no other routine or standard HPV screening guidelines for those who do not have a cervix. Your partner(s) should talk to their healthcare provider about signs and symptoms to watch for.

Can I have new sexual partners in the future?

- Yes. It is always important to talk about how you will protect yourself during sexual activity (e.g., condoms and barrier protection) with any new sexual partners.

Does HPV mean my partner had other sexual partners during our relationship?

- No, having an oral HPV infection does not mean your partner was/is unfaithful.
- There should be no shame or blame associated with an HPV diagnosis.
- Some people with an Oral HPV infection report never having had oral sex, or have had only a few lifetime oral sex partners.

Will the HPV vaccine help me?

- The HPV vaccine prevents people from getting new HPV infections. It will not help clear an HPV infection you already have.
- It is not known at this time whether the vaccines can prevent cancer recurrences (the cancer coming back) in the oropharynx.
- The HPV vaccine is approved by Health Canada for people up to the age of 45. Unvaccinated people aged 45 and under should talk to their doctor about the benefits of the vaccine.

Information on HPV-positive Oropharyngeal Squamous Cell Cancer (OPSCC)

How does Oral HPV cause OPSCC?

- We do not know how Oral HPV causes cancers in the head and neck.
- Performing oral sex and having many oral sex partners are strongly linked to Oral HPV infection and increase your chances of having HPV-positive OPSCC.
- If the body is not able to clear the HPV infection, HPV can cause damage to normal cells, which may cause a tumour to grow.
- It takes many years (often 20 to 30 years) for the HPV-infected cells to become cancer.
- Some of the signs and symptoms at diagnosis may include a lump in the neck, a sore throat that doesn't go away, difficulty/pain when swallowing, earache, or problems opening the jaw.

How do I know if Oral HPV caused my cancer?

- When OPSCC is diagnosed, the tumour itself can be tested for HPV.
- In Ontario, biopsies are tested for the over production of a protein called p16 because this over production is a characteristic of HPV-positive OPSCC.

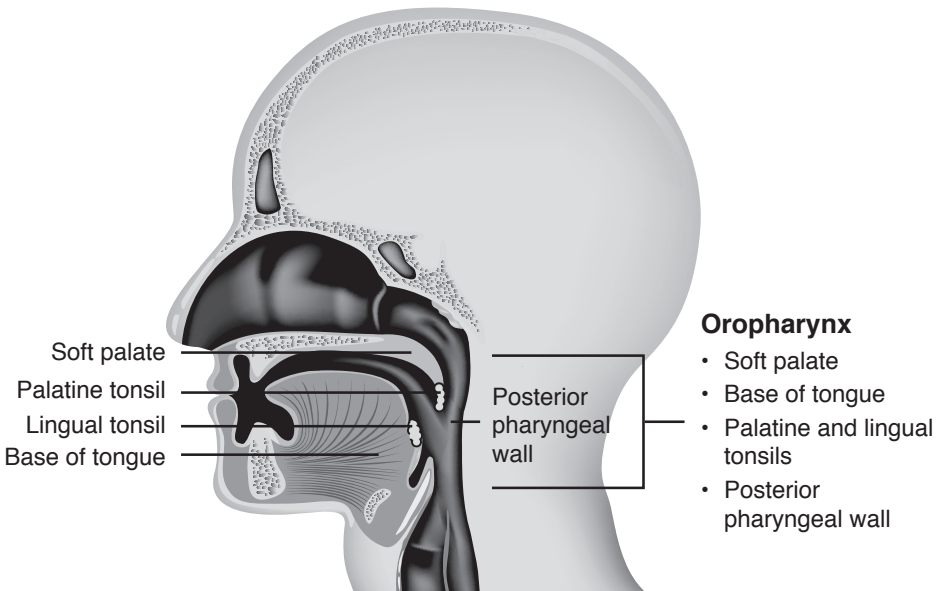
Can I get another cancer from HPV?

- The risk of getting a second cancer from HPV in the future is low. You will be regularly checked by your oncologist for at least 5 years. Report any new symptoms or concerns to your doctors.

Is my spouse/partner at a higher risk of this cancer?

- The rate of Oral HPV infection among spouses/partners is the same as the general population.
- The risk of developing HPV-associated cancers among spouses/partners may be slightly higher than the general population. These cancers are rare.
- Your partner should discuss any symptoms or concerns with his or her doctor.

Side view of the Oropharynx



Information on Treatment and Prognosis of HPV-positive Oropharyngeal Squamous Cell Cancer (OPSCC)

How is HPV-positive OPSCC treated?

- Both HPV-positive OPSCC and HPV-negative OPSCC are treated the same way.
- Treatment decisions are based on the size and location of the tumour, stage of the disease, overall health of the patient, and the patient's wishes.
- You might have surgery, radiation, and/or chemotherapy to treat your cancer.

What are the side effects of treatment?

- Treatment can result in short-term (up to 3 months) and long-term (beyond 3 months) side effects such as:
 - Skin reactions in the area that is treated
 - Trouble swallowing
 - Changes in speech and/or taste
 - Dry mouth and throat
 - Dental issues
 - Ringing in the ears
 - Loss of hearing.
- Each patient's recovery can be different. If you have more questions on side effects, ask your health care team for more information or check our patient education material on side effects from treatment. **Visit sunnybrook.ca/HPV-OPSCC**

Does an HPV status affect the chance of my cancer being cured?

- HPV-positive OPSCC have higher cure rates than HPV-negative OPSCC because they seem to be more sensitive to chemotherapy and radiation therapy. Researchers are still studying why this happens.
 - People with cancer who do not use tobacco or alcohol live longer and are less likely to get new cancers.
 - People with any head and neck cancer should stop using tobacco and limit alcohol use. Check [sunnybrook.ca/quitsmoking](https://www.sunnybrook.ca/quitsmoking) for help or talk to your healthcare team.
 - The stage of your disease can help predict survival outcomes. To find out the stage of your cancer, you may require more tests, such as CT and/or MRI scans. Once these tests are done, you can ask your oncologist for the stage.
 - The approximate percentage of patients with HPV-positive OPSCC who are alive 5 years after treatment depends on the stage of their disease. Please note that the following estimates are generalized and do not consider the full picture. Your oncologist will have a better understanding of your personal circumstances.
 - **Stage 1** = 80 – 90%
 - **Stage 2** = 75 – 80%
 - **Stage 3** = 50 – 70%
 - **Stage 4** (rare, less than 10% of patients) = 25 – 35%
- For more information on staging, follow the link at [sunnybrook.ca/HPV-OPSCC](https://www.sunnybrook.ca/HPV-OPSCC)

Information on Support and Rehabilitation Programs at the Odette Cancer Centre

- Hearing an HPV diagnosis in addition to your cancer diagnosis can affect the mental health of both you and your family.
- Up to 40% of people who get cancer treatment need support. Some people get counselling or medication for sleep, mood or anxiety. It is important to get support if you need it.
- The Patient and Family Support Program offers support for patients and family members with emotional, social and financial difficulty. You can drop in to make an appointment or ask for a referral to social work, psychology or psychiatry from your oncology team.
 - Visit **[sunnybrook.ca/odette](https://www.sunnybrook.ca/odette)** or call 416-480-4623 for more information
- Head and neck cancer and treatments can make it difficult to eat well, especially if you have side effects. Clinical Nutrition Services are part of your care and include access to a Registered Dietitian who can answer your questions and concerns on nutrition, nutrition-related side effects from treatment, and provide information about nutritional supplements.

- Speech Language Pathologists are professionals who can help address your voice, speech, and swallowing issues that can result from head and neck cancer and its treatments. They can test these oral functions before, during and after treatment, and create a personalized rehabilitation plan with you.
- Lymphedema is swelling that is caused by a large amount of lymph fluid in the tissues and may be caused by the tumour or from treatment. Talk to your oncologist if a referral to the Lymphedema Clinic is right for you.
- You can also seek support for yourself, family and children through Gilda's club and Wellspring, which are non-profit agencies that offer free programming for emotional and practical support, including return to work classes and advice on benefits.
- If you have any questions about your head and neck cancer, please call the Head and Neck Nursing team:
 - Available Monday to Friday, 9:00am to 4:30pm
416-480-5000

Visit **[sunnybrook.ca/HPV-OPSCC](https://www.sunnybrook.ca/HPV-OPSCC)**
for more resources

Odette Cancer Centre
2075 Bayview Avenue
Toronto, Ontario M4N 3M5
sunnybrook.ca/odette

