Oral Cancer
Understanding your diagnosis

When you first hear that you have cancer you may feel alone and afraid. You may be overwhelmed by the large amount of information you have to take in and the decisions you need to make.

“All I could hear was ‘cancer.’ I heard my doctor say something like, ‘We’re going to try to get the surgery done as soon as possible.’ I didn’t hear one word after that.”

The introductory information in this brochure can help you and your family take the first steps in learning about oral cancer. A better understanding may give you a feeling of control and help you work with your healthcare team to choose the best care for you.

For more information
You can find more in-depth information about oral cancer on cancer.ca. Or call us at 1-888-939-3333 to learn more about cancer, diagnosis, treatment, support and services near you.
What is cancer?

Cancer is a disease that starts in our cells. Our bodies are made up of trillions of cells, grouped together to form tissues and organs such as muscles and bones, the lungs and the liver. Genes inside each cell order it to grow, work, reproduce and die. Normally, our cells obey these orders and we remain healthy.

But sometimes the instructions in some cells get mixed up, causing them to behave abnormally. These cells grow and divide uncontrollably. After a while, groups of abnormal cells form lumps, or tumours.

Tumours can be either benign (non-cancerous) or malignant (cancerous). Benign tumour cells stay in one place in the body and are not usually life-threatening. Malignant tumour cells are able to invade nearby tissues and spread to other parts of the body. It’s important to find and treat malignant tumours as early as possible. In most cases, finding cancer early increases the chances of successful treatment.

Cancer cells that spread to other parts of the body are called metastases. The first sign that a malignant tumour has spread (metastasized) is often swelling of nearby lymph nodes, but cancer can spread to almost any part of the body.

Cancers are named after the part of the body where they start. For example, cancer that starts in the mouth but spreads to the lungs is called oral cancer with lung metastases.
What is oral cancer?

Oral cancer starts in the cells of the mouth (oral cavity).* The oral cavity is made up of many parts:

- lips
- tongue
- inside of the lips and cheeks
- hard palate (roof of the mouth)
- floor of the mouth (under the tongue)
- gums and teeth

The lining of the mouth protects the tissues and organs that make up the oral cavity. The lining is exposed to everything you eat, drink and breathe.

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* Cancer of the salivary glands is different from other oral cancers. For information about cancer of the salivary glands, contact our Cancer Information Service at 1-888-939-3333.
Diagnosing oral cancer

Your doctor may suspect you have oral cancer after taking your medical history and doing a physical exam. The exam includes looking at the roof and floor of your mouth, the back of your throat and the insides of the cheeks and lips. Your tongue is pulled gently so that the doctor can carefully check the sides of the tongue and underneath it. The doctor also feels the lymph nodes in your neck. To confirm the diagnosis, your doctor then arranges special tests. These tests may also be used to “stage” the cancer and help plan treatment.

Symptoms of oral cancer: The mouth can be examined easily by a doctor or dentist. The signs of oral cancer are often seen in the early stages of the disease during a routine checkup. The most common signs and symptoms of oral cancer include:

- patches that are white or red (or both) inside the mouth or on the lips
- a sore that does not heal on the lip or in the mouth
- a lump or growth on the lip or in the mouth, including on the tongue
- thickening in the cheek
- bleeding or pain in the mouth
- an earache that doesn’t go away
- loose teeth or dentures that no longer fit well
- problems speaking clearly
- a lump or swelling in the neck or jaw
- numbness of the tongue or lips
Other health problems can cause some of the same symptoms. The process of diagnosis may seem long and frustrating, but it is important for the doctor to make sure there are no other possible reasons for a health problem.

Your doctor will do one or more of the following tests to make a diagnosis.

**Endoscopy**: Your doctor may do an endoscopic exam to check your throat, windpipe and lungs. An endoscopy uses a thin, flexible tube with a light at the end (called an endoscope). The doctor inserts the tube through your nose or mouth. If an abnormal area is found, the doctor may take several samples of tissue through the endoscope to examine under a microscope. This is called an endoscopic biopsy. During an endoscopy, you will probably be given a mild anesthetic (freezing). If the doctor takes tissue samples, you may need a general anesthetic (you will be unconscious). You will have a sore throat for a couple of days.

**Exfoliative cytology**: This test can find cell changes. Your doctor scrapes a small sample of cells from a suspicious area and puts it on a glass slide. The sample is stained with a dye and looked at under a microscope. If the cells appear abnormal, doctors may then do a biopsy.
**Biopsy:** A biopsy is usually needed to make a definite diagnosis of cancer. Cells are taken from the body and checked under a microscope. If the cells are cancerous, they will be studied further to see how fast they are growing. Depending on the type of biopsy used, you may have a local or a general anesthetic. A general anesthetic is used if the abnormal area or tumour is in a sensitive area, such as the upper throat or the base of the tongue.

**Imaging studies:** Imaging studies let your healthcare team look at your tissues, organs and bones in more detail. They will use x-rays, CT scans, MRIs, ultrasounds or PET scans to see the size of the tumour and if it has spread. These tests are usually painless, and you don’t need an anesthetic.

If your doctor suspects that you have oral cancer, you will likely have a CT or MRI scan of your head and neck. To see if you have cancer in your jaw bone and to check the gums, you may have a panoramic x-ray. During this procedure, a special x-ray machine moves around your head in a half circle from ear to ear to create a wide image of the teeth and jaw bone.

**Further testing:** Your doctor may order more tests to find out if the cancer has spread and to help plan your treatment.
Will I be OK?

Most people with cancer want to know what to expect. Can they be cured?

A prognosis is your doctor’s best estimate of how cancer will affect you and how it will respond to treatment. A prognosis looks at many factors including:

• the type and stage of the cancer
• the location of the tumour and whether it has spread
• your age, sex and overall health

Even with all this information, it can still be very hard for your doctor to say exactly what will happen. Each person’s situation is different.

Your doctor is the only person who can give a prognosis. Ask your doctor about the factors that affect your prognosis and what they mean for you.
Staging

Once a definite diagnosis of cancer has been made, the cancer is given a stage. This information helps you and your healthcare team choose the best treatment for you.

The cancer stage describes the tumour size and tells whether it has spread.

For oral cancer, there are 5 stages.*

<table>
<thead>
<tr>
<th>Stage</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>This is a very early stage of oral cancer. Cancer cells are found only in the cells in the lining of the lips or mouth. Stage 0 is also called carcinoma in situ.</td>
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<tr>
<td>1</td>
<td>The tumour is 2 cm or less.</td>
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<tr>
<td>2</td>
<td>The tumour is larger than 2 cm but smaller than 4 cm.</td>
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<tr>
<td>3</td>
<td>The tumour is larger than 4 cm or the cancer cells have spread to nearby lymph nodes (and the lymph node tumour is 3 cm or less).</td>
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<tr>
<td>4</td>
<td>The cancer has spread to the lymph nodes (and the lymph node tumour is larger than 3 cm) or cancer cells have spread to other parts of the mouth or body.</td>
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* This table summarizes the stages of oral cancer according to the Union for International Cancer Control (UICC) and the American Joint Committee on Cancer (AJCC). For more in-depth information, visit cancer.ca.
Treatments for oral cancer

Your healthcare team considers your general health and the type and stage of the cancer to recommend the best treatments for you. You’ll work together with your healthcare team to make the final treatment choices. Talk to them if you have questions or concerns.

See a dentist before starting treatment

Some treatments for oral cancer may make your mouth sensitive and put you at a higher risk of infection. It’s important to have a full dental exam and get any needed dental work done before you start treatment.

For oral cancer, you might receive one or more of the following treatments.

**Surgery**: Surgery is often used to treat oral cancer. A decision to have surgery depends on the size of the tumour and where it is. Very small tumours may be treated with a simple operation under a local or general anesthetic.

For larger tumours, surgery is done under a general anesthetic, and you will stay in the hospital for several days after the surgery. The surgeon removes the entire tumour and some of the healthy tissue around it. If cancer has spread into the bone, part of the bone is also removed.

If the cancer has spread to the lymph nodes in the neck or there is a high risk of the cancer spreading to them, the surgeon removes these lymph nodes. Other tissues in the neck may also be removed. This is called a neck dissection.
You may also need reconstructive surgery. Surgery to remove cancer from your oral cavity may affect your ability to chew, swallow or talk. It can also change how your face looks. Reconstructive surgery (also called plastic surgery) can be done to repair or rebuild parts of the lips, mouth, throat and neck.

If the surgery is going to make it hard for you to swallow, an intravenous (IV) drip into a vein or a feeding tube in your nose or your abdomen is used to give you liquids and nutrients until you can eat and drink on your own.

It’s important to talk to your surgery team before your operation so that you know what to expect and how it will affect you. After surgery, you may have some pain or bleeding. These side effects are temporary and can be controlled. Surgery may also cause swelling. If lymph nodes were removed, the swelling may last a long time.

Eating properly after oral surgery can be hard, so ask your healthcare team to refer you to a registered dietitian. A nutrition plan can be made especially for you to help you maintain your health, well-being and quality of life.

**Radiation therapy:** In external beam radiation therapy, a large machine is used to carefully aim a beam of radiation at the tumour. The radiation damages the cells in the path of the beam – normal cells as well as cancer cells. In brachytherapy, or internal radiation therapy, radioactive material is placed directly into or near the tumour.
You may have a mask made especially for you before radiation therapy. This mask is worn for the treatment planning and for all radiation treatments. The mask helps make sure you’re in the exact same position for every treatment and helps stop your head and neck from moving during treatment.

**Radiation therapy works better if you avoid tobacco**

To get the most out of radiation treatment for oral cancer, experts recommend that you:

- Quit smoking, if you’re a smoker.
- Avoid second-hand smoke.

Radiation side effects depend on what part of the head or neck receives the radiation. You may feel more tired than usual or notice changes to the skin (it may be red or tender) where the treatment was given. Radiation for oral cancer makes the mouth and throat dry and sore. This can make it hard for you to swallow. Radiation may also affect your teeth and gums or how well dentures fit. These side effects result from damage to normal cells. The side effects usually go away when treatment is over and the normal cells repair themselves. A few side effects, such as dry mouth, can last a long time.
Chemotherapy: Chemotherapy is sometimes used to control pain from oral cancer or to prepare cells for radiation. Chemotherapy uses drugs to treat cancer. Chemotherapy drugs may be given as pills or by injection (with a needle). They interfere with the ability of cancer cells to grow and spread, but they also damage healthy cells. Although healthy cells can recover over time, you may experience side effects from your treatment like constipation, diarrhea, fatigue, nausea, vomiting or an increased risk of infection.

For more information on treatment, you may want to read our booklets Chemotherapy and Other Drug Therapies and Radiation Therapy.

Clinical treatment trials: Clinical treatment trials investigate new approaches to treating cancer, such as new drugs, new types of treatments or combinations of existing treatments. They are closely monitored to make sure that they are safe and effective for the participants. Ask your doctor if any clinical trials are available as a suitable treatment option for you. You may benefit and so may future cancer patients.

Our brochure Clinical Trials has more information, including how to find a clinical trial.

Complementary therapies: Complementary therapies – for example, massage therapy or acupuncture – are used together with conventional cancer treatments, often to help ease tension and stress as well as other side effects of treatment. They don’t treat the cancer itself. More research is needed to understand if these therapies are effective and how they work.
Alternative therapies are used instead of conventional treatments. Alternative therapies haven’t been tested enough for safety or effectiveness. Using alternative treatments alone for cancer may have serious health effects.

If you’re thinking about using a complementary or alternative therapy, learn as much as you can about the therapy and talk to your healthcare team. It’s possible that the therapy might interfere with test results or other treatments.

**Side effects of treatment**: Some cancer treatments cause side effects, such as fatigue, hair loss or nausea. Because treatments affect everyone differently, it’s hard to predict which side effects – if any - you may have.

Side effects can often be well managed and even prevented. If you’re worried about side effects, tell your healthcare team about your concerns and ask questions. They can tell you which side effects you should report right away and which ones can wait until your next appointment.

If you notice any side effects or symptoms that you didn’t expect, talk to a member of your healthcare team as soon as possible. They’ll help you get the care and information you need.
After treatment

Follow-up care helps you and your healthcare team monitor your progress and your recovery from treatment. At first, your follow-up care may be managed by one of the specialists from your healthcare team. Later on, it may be managed by your family doctor.

The schedule of follow-up visits is different for each person. You might see your doctor more often in the first year after treatment and less often after that. After treatment has ended, visit your dentist for regular checkups and inspect your mouth regularly.

Report any changes in your mouth, new symptoms and symptoms that don’t go away to your doctor without waiting for your next scheduled appointment.

The end of cancer treatment may bring mixed emotions. You may be glad the treatments are over and look forward to returning to your normal activities. But you could feel anxious as well. If you are worried about your treatment ending, talk to your healthcare team. They’re there to help you through this transition period.

Rehabilitation: Treatment for oral cancer may affect your appearance or your ability to eat and speak. Rehabilitation programs can help you return to your normal activities. Rehabilitation may include being fitted with a prosthesis (an artificial dental structure) to help you eat and talk normally, speech therapy, nutrition counselling or other services.
Eating well: After treatment for oral cancer, you may find it hard to eat because your mouth is dry or sore, or your sense of smell and taste has changed.

If your mouth is dry, try eating thick soups, puddings, milkshakes and soft foods moistened with sauces or gravies. If you don’t feel hungry, you may find it easier to eat smaller meals and snacks more often throughout the day, rather than eating 3 large meals. It is important to eat well so that you get enough calories and protein to help you maintain your weight and strength during and after your cancer treatments.

Your doctor or dietitian can give you more information about maintaining a healthy diet.

Self-esteem, body image and sexuality: It’s natural to be concerned about your self-esteem, body image and sexuality. Often this is because oral cancer and its treatment may lead to changes in a person’s appearance, such as scars or difficulty speaking. You may be worried about how your body looks after treatment or that you may be rejected. It may help to talk about these feelings with someone you trust. Your doctor can also refer you to specialists and counsellors who can help you with the emotional side effects of oral cancer treatment.
Many sources of help are available for people with cancer and their caregivers.

**Your healthcare team:** If you need practical help or emotional support, members of your healthcare team may be able to suggest services in your community or refer you to cancer centre staff or mental health professionals.

**Family and friends:** People closest to you can be very supportive. Accept offers of help. When someone says, “Let me know how I can help,” tell them what they can do. Maybe they can run errands, cook a meal or drive you to your doctor’s office.

**People who’ve had a similar experience:** Talking with and learning from others who’ve had similar experiences can be helpful. Consider visiting a support group or talking with a cancer survivor in person, over the telephone or online. Try more than one option to see which one works best for you.

**Yourself:** Coping well with cancer doesn’t mean that you have to be happy or cheerful all the time. But it can mean looking after yourself by finding relaxing, enjoyable activities that refresh you mentally, spiritually or physically. Take some time to find coping strategies to help you through this experience. You may also want to talk to a counsellor for more help.
Talking to someone who’s been there

If you would like to talk to someone who’s had a similar cancer experience, you can connect by phone with a trained volunteer who will listen, provide hope and suggest ideas for coping – all from the unique perspective of someone who’s been there.

Register for this free program at match.cancer.ca or call us at 1-888-939-3333.

Want to connect with people online?

If you’d like to join our online community, visit CancerConnection.ca. You can read news, join discussion groups, get support and help others at the same time. You’ll find caring, supportive people there.
What causes oral cancer?

Most people diagnosed with oral cancer are over the age of 45. There is no single cause of oral cancer, but some factors increase the risk of developing it. Some people can develop oral cancer without any risk factors, while others who have these factors do not get it.

Risk factors for oral cancer include:

• smoking or chewing tobacco or using snuff, especially if you also drink alcohol
• drinking alcohol, especially if you also smoke, chew tobacco or use snuff
• chewing betel nut
• infection of the oral cavity with the human papillomavirus (HPV)
• precancerous conditions or previous cancer in the mouth
• a family history of squamous cell carcinoma
• sun exposure to the lips
• a diet low in vegetables and fruit
• a weakened immune system
• conditions of the mouth, such as graft-versus-host disease (GVHD) or lichen planus
Canadian Cancer Society
We’re here for you.

When you have questions about treatment, diagnosis, care or services, we will help you find answers.

Call our toll-free number 1 888 939-3333.

Ask a trained cancer information specialist your questions about cancer. Call us or email info@cis.cancer.ca.

Connect with people online to join discussions, get support and help others. Visit CancerConnection.ca.

Browse Canada’s most trusted online source of information on all types of cancer. Visit cancer.ca.

Our services are free and confidential. Many are available in other languages through interpreters.

Tell us what you think
Email cancerinfo@cancer.ca and tell us how we can make this publication better.
What we do

The Canadian Cancer Society fights cancer by:

• doing everything we can to prevent cancer
• funding research to outsmart cancer
• empowering, informing and supporting Canadians living with cancer
• advocating for public policies to improve the health of Canadians
• rallying Canadians to get involved in the fight against cancer

Contact us for up-to-date information about cancer and our services or to make a donation.