Cancer of the upper aerodigestive tract (cancer of the mouth, throat, voice box and sinuses)

Information for the public
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About this information

NICE guidelines provide advice on the care and support that should be offered to people who use health and care services.

This information explains the advice about cancer of the upper aerodigestive tract that is set out in NICE guideline NG36.

Does this information apply to me?

Yes, if you’re an adult or young person aged 16 or over with cancer or suspected cancer of the upper aerodigestive tract, or their carer or parent.

Cancer of the upper aerodigestive tract

Your upper aerodigestive tract is the inside of your mouth (oral cavity), throat (nasopharynx, oropharynx and hypopharynx), voice box (larynx) and your sinuses (the air spaces in the bones of your face). This information covers a lump or growth of cancerous cells (a tumour) when it is found in any of those areas. Cancerous tumours grow in an uncontrolled way and spread rapidly, so it’s important to get the right treatment for you as soon as possible.
Your care team

A range of professionals who specialise in different areas of treatment or support may be involved in your care. These could include surgeons that specialise in cancer of the mouth, throat, voice box and sinuses, specialist nurses, radiologists (doctors and professionals who specialise in diagnosing and treating diseases using imaging technology such as X-rays), oncologists (doctors and professionals who specialise in treating cancer), pathologists (professionals who specialise in analysis of bodily fluids such as blood and urine, as well as tissues), speech and language therapists, dietitians (professionals who specialise in diet), dental therapists and your GP. These professionals work together in a special type of team called a multidisciplinary team, or MDT for short.

Working with you

Your care team should talk with you about upper aerodigestive tract cancer. They should explain any tests, treatments or support you should be offered so that you can decide together what is best for you. Your family, partner or carer can be involved in helping to make decisions, but only if you agree. If you’re a young person, your parent or carer may be involved in helping to make decisions. There are also questions after each section you can use to help you talk with your care team.

You may also like to read NICE’s information for the public on patient experience in adult NHS services. This sets out what adults should be able to expect when they use the NHS. We also have more information on the NICE website about using health and social care services.

Some treatments or care described here may not be suitable for you. If you think that your treatment does not match this advice, talk to your care team.

Finding out if you have cancer

At first, most people who have cancer of the mouth, throat, voice box or sinuses have symptoms like a sore throat that won't go away, wobbly teeth, or a lump. If your doctor thinks any of your symptoms might be cancer they'll arrange for you to have tests to find out. This could be a scan to look inside your body, or you may need to have a tissue sample taken for testing (for example by biopsy).
Testing neck lumps

If you have a neck lump that your doctor thinks may be cancer, they should offer you a needle test to confirm this. A needle, sometimes guided by ultrasound, is used to take a sample of tissue that can then be checked in a laboratory for cancer cells.

Working out what stage your cancer is at

If you are diagnosed with cancer, your doctor will work out what stage your cancer is. The stage describes the size of your cancer and if it has spread to anywhere else, and this helps in deciding what treatments should work best for you.

If your cancer has spread from the original (primary) tumour to somewhere else, it is called metastatic. It will usually be nearby, for example from a primary tumour in your throat into your lymph nodes.

If metastatic cancer is found, it's important to find the primary tumour so it can be treated as well. You may be offered a scan to do this. If a tumour is found, your doctor may offer you endoscopy or a biopsy to confirm it.

Finding out what's wrong (diagnosis)

- Can you tell me more about the tests/investigations you've offered me?
- What do these tests involve?
- Will they be painful?
- What's the difference between a biopsy and testing a lump with a needle?
- Where will the tests be carried out? Will I need to have them in hospital?
- How long will I have to wait until I have these tests?
- How long will it take to get the results of these tests?
- How will I find out my results?
- Will I need surgery to find out what's wrong?
About your cancer

- Can you tell me more about my type of cancer?
- Do I have metastatic cancer (cancer that has spread)?
- Can you explain what the staging and grading mean for the cancer I have?
- Is my cancer genetic? Are close relatives or my children likely to have the same sort of cancer too?

Information and support after your diagnosis

After your diagnosis has been confirmed, your care team should give you information and support to help you understand your cancer and how it will affect you and your life. They should also talk to you about the treatments you may have, and what side effects there may be.

You should be given the details of your key worker, who will be your main contact while you're having treatment, and information about any support groups for people with cancer similar to yours that you may like to join.

Some mouth, throat, voice box or sinus cancers are related to having a virus called human papillomavirus (or HPV). If you have an HPV-related cancer you'll get information about this too.

Making sure you and your family members, friends or carers stay informed

- Who is my key worker, and what's their role?
- Are there any support organisations in my local area?
- Can you provide any information aimed at my family/carers?
- I'm a family member or carer – what can I do to help and support the person with cancer?
- Is there any additional support that carer(s) might benefit from or be entitled to?
About HPV and cancer

- What does it mean if I have a diagnosis of human papillomavirus (HPV)-related cancer?
- Do my family need HPV vaccinations? Do I need any special treatment?

Treating your cancer

The best types of treatment for you will depend on where your cancer is, what type it is, and what stage it’s at (this means how advanced it is). Your treatment could include:

- radiotherapy
- chemotherapy
- surgery to remove the cancerous tissue (this could be laser treatment).

Sometimes it may work better if 2 or more treatments are used at the same time, for example radiotherapy and chemotherapy, or surgery followed by radiotherapy.

Your care team should talk with you about what treatment may work best for you with the type and location of your cancer, and what treatment options you have.

Making treatment choices

Sometimes you may have to make choices about how much treatment you want and of what type – for example you may be able to choose between laser treatment or radiotherapy. Different treatments can have different side effects, and might affect you in different ways. The choices you have and the outcomes might also be affected by how advanced your cancer is. For example, surgery to remove tumour tissue could damage your voice box or make it hard for you to swallow, but may work better to get rid of the cancer than radiotherapy or chemotherapy.

Some different types of cancer, and the treatments that may be used for it (alone or in combination), are:

- early squamous cell carcinoma of the larynx (surgery, radiotherapy)
- advanced squamous cell carcinoma of the larynx (surgery, radiotherapy, chemotherapy)
• early oral cavity carcinoma (surgery)
• squamous cell carcinoma of the oropharynx (surgery, radiotherapy, chemotherapy)
• squamous cell carcinoma of the hypopharynx (surgery, radiotherapy, chemotherapy)
• carcinoma of the nasopharynx (radiotherapy, chemotherapy)
• carcinoma of the paranasal sinuses (surgery, radiotherapy, chemotherapy)
• unknown primary (investigative surgery to try and find the tumour)
• mucosal melanoma (surgery, radiotherapy)

Your care team should talk to you about what should work best for you, why some options may not be good choices for you, and what the possible outcomes may be.

Stopping smoking

If you are a smoker, you’ll be advised to stop smoking. Continuing to smoke may have an effect on how your cancer grows, how well your treatment works and what the side effects are like. You should be offered help with quitting if you need it.

Breathing problems

If your cancer is making it difficult to breathe, you may be offered surgery to remove some of the cancer or a tracheotomy (breathing tube) while more treatment is planned. Your care team should also check to see if anything else is making it hard for you to breathe.

Treatments and care

• Can you tell me why you have decided to offer me this particular type of treatment? Are there any other options?
• Can you tell me why you have/haven't offered me a combination of treatments?
• What are the pros and cons of this treatment?
• What will it involve?
• How will it help me? What effect will it have on my symptoms and everyday life? What sort of improvements might I expect?

• What are the side effects of this treatment? How long will they last?

• How long will the treatment go on for?

• Are there any risks associated with this treatment?

• Will my speech be affected?

• Will I lose my sense of smell, or have a dry mouth?

• Will the treatment affect the way I look?

• Will I still be able to work?

• Could I meet someone who has had the same treatment as I might have to find out how they coped?

• Is there some other information (like a leaflet, DVD or a website I can go to) about the treatment that I can have?

Surgery

• Will I need to have an operation?

• What will the operation do?

• What are the risks?

• After the operation, will I be affected by what has been done?

Lifestyle

• Would it help my condition or how well my treatment works if I made some changes to my lifestyle, such as stopping smoking?

• Where can I get help to stop smoking?

Choosing not to have a treatment
Rehabilitation and support

During and after your cancer treatment, your care team should offer you support and rehabilitation treatment to help you recover and make sure you stay healthy. This could include:

- making sure you are able to eat and drink enough of the right type of foods
- arranging for a feeding tube to help with eating and drinking if you are having trouble swallowing
- swallowing and mouth-opening exercises
- voice therapy
- shoulder exercises if you find it difficult to move your shoulder after neck surgery.

After treatment

After your treatment you should have regular follow-up visits. These are to check your general health, how you're adjusting to any changes that happened because of your treatment, and also to check that the cancer has not come back. Your care team should give you information on symptoms to look out for that may show your cancer has come back, and on side effects that sometimes come on after treatment has ended (these are called late effects).

If you have had radiotherapy sometimes you can develop a late effect called osteoradionecrosis, though this is rare. This is when bone cells in the jaw die as a side effect of the radiation treatment that was used to kill the cancer cells. If you have osteoradionecrosis, you may need surgery to remove the affected area. You may also be offered a treatment called hyperbaric oxygen therapy, or medicine instead of surgery, but this should only happen as part of a clinical trial (this is when a new type of treatment is being tested, but you will only take part and get the new treatment if you agree to it). If you aren't sure why you have been offered a treatment, you should talk to your care team.
Can you tell me about the chances of my cancer coming back?

Can you tell me more about late effects of treatment? Will I get them?

Terms explained

**Biopsy**

This is a when a small sample of tissue is removed from part of the body. The sample is examined under a microscope to look for abnormal cells.

**Carcinoma**

This is a medical word for the type of cancer that starts in cells that are the lining of something. For example, the inside of your mouth.

**Endoscopy**

An endoscope is a long, thin, flexible tube that has a light and a video camera at one end that sends pictures back to a TV screen. The endoscope is inserted through your mouth and down your throat so doctors can examine inside of your body.

**Larynx**

This is your voice box, and holds your vocal cords.

**Melanoma**

This is a type of cancer of lining or skin cells.

**Mucous membrane**

This is the lining layer of cells inside your nose, mouth and throat that come into contact with the air.
**Nasopharynx, oropharynx and hypopharynx**

These are the upper, middle and lower parts of your throat.

**Oral cavity**

This is the inside of your mouth. It doesn't include your lips.

**Sinuses**

The sinuses are small air spaces inside your head, found behind your nose, eyes and cheeks.

**Stage**

The stage of your cancer describes how big it is and whether it has spread to anywhere else. For the stages of cancer used in this guideline you will have a T number and an N number (for example, T1N0). The T and N stand for:

- **T0**: this means there is no primary tumour, but you may have some abnormal cells that are precancerous.
- **T1 to T4**: this shows the increasing size of the primary tumour, with 1 being smallest and 4 largest.
- **N0**: no lymph nodes contain cancer cells.
- **N1 and upwards**: increasing numbers of lymph nodes contain cancer cells.

**Sources of advice and support**

- Macmillan Cancer Support, 0808 808 00 00
  [www.macmillan.org.uk](http://www.macmillan.org.uk)
- Cancer Research UK, 0808 800 4040
  [www.cancerresearchuk.org](http://www.cancerresearchuk.org)
- Throat Cancer Foundation
  [www.throatcancerfoundation.org](http://www.throatcancerfoundation.org)
You can also go to NHS Choices for more information.

NICE is not responsible for the quality or accuracy of any information or advice provided by these organisations.

Other NICE guidance

- Stop smoking services (2007) NICE guideline PH10
- Nutrition support for adults (2006) NICE guideline CG32

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Accreditation

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