

Living with Mouth and Oropharyngeal cancer - A Quick Guide



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This is a brief summary of the information on 'Living with mouth and oropharyngeal cancer' from CancerHelp UK. You will find more detailed information on the website.

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Coping with mouth cancer

It can be very difficult coping with a diagnosis of cancer, both practically and emotionally. At first, you are likely to feel very confused and upset at first.

As well as coping with the fear and anxiety that a diagnosis of cancer brings, you have to work out how to manage practically.

Try to remember that you don't have to sort everything out at once. It may take some time to deal with each issue. Do ask for help if you need it though.

On top of this, you may also be trying to quit smoking. This can be extremely difficult, especially if you have smoked for many years.

The coping with cancer section of CancerHelp UK contains lots of information you may find helpful. There are sections on your feelings, telling people about your cancer, helping yourself, where to get outside help and financial matters.

Eating after mouth cancer

It can be quite difficult to cope with the changes to eating that mouth or oropharyngeal cancer can cause. But support available for you.

Difficulty swallowing or chewing

After radiotherapy you will probably have difficulty swallowing for a while. Surgery to the mouth area will make eating and swallowing difficult until you recover. You may have a tube into your stomach for liquid feeds. You may also have difficulty chewing. There is information on a soft



diet in the coping with cancer section of CancerHelp UK.

Dry mouth

Radiotherapy to your mouth often causes a dry mouth. Some people find the dryness is permanent. Your doctor can prescribe artificial moisteners for your mouth or stimulants for your salivary glands. You may find it helps to carry a bottle of water with you all the time, so you can keep taking small sips.

Changes in taste and smell

You may notice changes in the way your food tastes. Try eating different foods, or meals with varied textures.

After your treatment, you need to build yourself up again. Eating little and often is easiest to cope with. You could ask your doctor to prescribe you some meals in a drink. A dietician will be able to help you plan a suitable diet and can give advice on supplements.

Changes in your appearance due to mouth cancer

Surgery involving the jaw, tongue, mouth, lips and throat may change the way you look. But modern surgical techniques and reconstructive surgery are much better than in the past. You are less likely to have too much scarring, even with very big operations.

Your surgeons will try to position scars inside the creases already on your face. And with time, many scars will fade and be far less visible. If you need to have bones removed from your face, your surgeon can often reconstruct them so that they look normal from the outside.

Surgery to the lips is harder to hide. So if you have cancer in this area, it is likely that you will have to cope with changes in the way you look. If you have a hole in your neck to breathe through (a breathing stoma) you may also feel very self conscious and find it hard to cope.

How surgery may affect your self esteem

How you look is an important part of your self esteem. It can be very hard to accept sudden changes in your looks that you are not happy with. It is not unusual for people who have had surgery to their face to feel very angry, confused and upset for some time afterwards. The important thing to remember is that the people most important to you will not think of you any differently as a person.

Things that may help you cope

There are several things that may help you cope with changes in your looks. These include doing things at your own pace and getting any help and support you need. You can find out about these on CancerHelp UK.

Changes in your speech due to mouth cancer

Depending on your treatment and the type of mouth or oropharyngeal cancer you have, you may have some changes in your speech. Speech changes are more likely with cancer of the tongue, soft palate or lips. They can also occur if you've had any teeth removed during surgery, or part or all of your voice box (larynx) has been removed.

Your voice may be quieter, huskier or sound as if you have a cold. Or you may slur some of your words or have trouble



pronouncing some sounds. This may be temporary and get better once any swelling from surgery has gone down. But sometimes it is permanent. Having a dry mouth after radiotherapy can also make it difficult to speak. Finding that you can no longer talk as fluently as you used to can be very distressing and frustrating.

You will have speech and language therapy if you have any of these problems. This may only be for a short time. But if the problems are more long term, you will continue to have speech and language therapy for some months after treatment.

You may find it useful to carry a small notebook and pen to write notes to people if you need to. Typewriters or electronic notebooks are another way you can communicate. There are a number of different small portable machines.

Having a breathing stoma due to mouth cancer

A breathing stoma is a hole (opening) made in the skin in front of your neck to allow you to breathe. It is placed at the base of your neck. Through this hole, air enters and leaves your windpipe (trachea) and lungs. You may need a stoma if your mouth or oropharyngeal cancer is blocking your throat and it is too big to completely remove. Or if you have swelling in and around your voice box after radiotherapy.

These situations are most likely to happen with very large tumours of the tongue and oropharynx. Your surgeon will make the stoma when you have your operation to remove your cancer.

Bear in mind that this is a rare operation for cancer of the tongue and oropharynx. And most stomas for head and neck cancer are temporary. Before you have surgery for your type of cancer, ask your doctor if you will have a breathing stoma and how long it is likely to stay in for. If you still have your voice box and the stoma is temporary, it is called a tracheostomy. You may only need to have a temporary tracheostomy

If you have had your voice box removed, you will have a permanent stoma to breathe through. You need this because the connection between your windpipe and mouth has gone. The stoma is called a tracheostomy or laryngectomy stoma.

There is detailed information about starting out with a breathing stoma and life with a breathing stoma in the cancer of the larynx section of CancerHelp UK.

Mouth and oropharyngeal cancer and your sex life

Any changes in your appearance caused by your cancer may make you feel less confident about sex. These changes affect the way you feel about yourself and how you think others see you. Try talking to your partner about these feelings. It's hard for them to understand unless you explain how you feel. If you are able to talk to your partner about your worries, you will both gradually get used to your new situation and things will feel less awkward. A caring and loving partner can help to ease your concerns.

Sometimes speech difficulties can affect your lovemaking. If you have learned another way to talk, then you can use this. But it may take more effort and change some of the spontaneous moments you



and your partner might be used to. Remember, talking is not necessary during many sexual situations. Eye contact and touching are very powerful ways of showing your feelings.

You may find it helps to talk to your nurse or doctor about difficulties with your sex life after treatment. They can refer you for specialist help if needed.

There is more about sex after cancer in the coping with cancer section of CancerHelp UK.

What to ask your doctor about living with mouth cancer

- How will my treatment affect me?
- Will I ever get back to normal, or will I have some long term effects?
- How will my speech be affected?
- How will I communicate with people after my operation?
- How will my breathing be affected?
- Will my hearing be affected?
- How will I look after my operation?
- What can be done to hide any scars I may have?
- Will my treatment affect my sex life?
- If I have difficulty eating, who can I go to for help?
- Will I need a special diet?
- Is there anything I shouldn't eat?
- Will I need any extra vitamins or other diet supplements?
- How do I see a dietician?
- Will I be able to go back to work?
- Where can I get help with claiming benefits and grants?
- What practical help is available?
- Why did this happen to me?
- Are my children at risk of getting a mouth or oropharyngeal cancer?

- Where can I get help dealing with my feelings?
- Can you refer me for counselling?
- Do I have to pay for counselling?
- Could you refer me to a Macmillan nurse?

Mouth cancer organisations

Cancer Research UK

Main website: www.cancerresearchuk.org

Patient information website:

<http://cancerhelp.cancerresearchuk.org>

Cancer Information Nurses phone: 0808 800 4040

Changing Faces

Phone: 0845 4500 275

Website: www.changingfaces.org.uk

Email: info@changingfaces.org.uk

Let Face It

Phone: 01843 833 724

Website: <http://www.lets-face-it.org.uk>

Email: chrisletsfaceit@aol.com

Saving Faces - The Facial Surgery Research Foundation

Phone: 020 3465 5755

Website: <http://www.savingfaces.co.uk>



Notes

More information

For more information about mouth and oropharyngeal cancer, visit our website <http://cancerhelp.cancerresearchuk.org>

You will find a wide range of detailed, up to date information for people affected by cancer, including a clinical trials database that you can search for cancer trials in the UK. You can view or print the information in a larger size if you need to.

For answers to your questions about cancer call our Cancer Information Nurses on **0808 800 4040** 9am till 5pm Monday to Friday

Adapted from Cancer Research UK's Patient Information Website CancerHelp UK in October 2011. CancerHelp UK is not designed to provide medical advice or professional services and is intended to be for educational use only. The information provided through CancerHelp UK and our nurse team is not a substitute for professional care and should not be used for diagnosing or treating a health problem or disease. If you have, or suspect you may have, a health problem you should consult your doctor. © Cancer Research UK 2011. Cancer Research UK is a registered charity in England and Wales (1089464) and in Scotland (SC041666).