

Supporting

HEAD & NECK CANCERS



A guide to making your journey as easy as possible for you and those closest to you

www.mouthcancerfoundation.org





WELCOME

Most types of cancer are decreasing in number in the developed world but some head and neck cancers are becoming more common. There are a number of reasons, some of which are discussed in this book.

Whatever the reason, being diagnosed with cancer always comes as a blow. Much of the apprehension stems from uncertainty about how the treatment and recovery will progress and what procedures may be necessary during this journey. To address this, the book explains the steps patients may need to take and the effects certain treatments may have. As with all cancers the earlier the diagnosis the better the outcome. This volume also contains a section on what to look

“The challenges of living with cancer are shared by family and friends who will also find valuable information on these pages.”

out for and stresses the importance of reporting anything suspicious to a health care professional as quickly as possible.

The challenges of living with cancer are not confined to the sufferer but are shared by family and friends who will also find valuable information on these pages.

I'm delighted to have been asked to write an introduction to this book which I firmly believe will be of great use to everyone affected by head and neck cancer.

With my very best wishes

Philip Lewis

BDS President Mouth Cancer Foundation



FOREWORD

I was diagnosed with Mouth Cancer in August 2008 and had surgery a month later. At the time I was 37 years old and had 5 young children. Despite putting on a brave face to those around me, I felt inwardly devastated. I was so scared about the effects of my surgery – even whether I would survive. I could not communicate how I felt to my loved ones as I thought that this was a battle I was facing on my own.

At the time, the internet was still very much in its infancy but whilst searching for “Mouth Cancer” I happened across the website for the Mouth Cancer Foundation. It was through the information that I found there and through reading survivors’ stories and having the opportunity to communicate, via the Forum, with others who had made the same journey, that I started to make sense of what was happening to me. Having the opportunity to ask questions made me realise that I was not on my own. But, by being a cancer sufferer and survivor I was now part of a big worldwide family who are always there to support each other.

“Nothing can possibly prepare you for being told those words ‘I’m very sorry to say you have Cancer’.”



There was no book that you could buy that would prepare me for what I would experience. I wish there had been. I now realise that my feelings at the time were perfectly normal and are common amongst cancer patients.

Having a source of reference following my diagnosis would have been invaluable to me both emotionally and practically, and I welcome the publication of this handbook and hope that future patients find it useful and informative as they embark on their own cancer journey”.

Rachel Parsons

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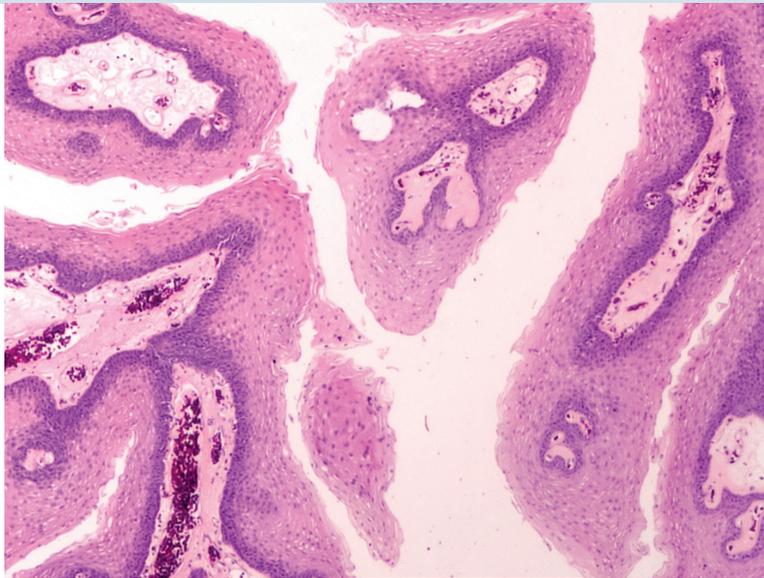
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HOW HEAD AND NECK CANCERS ARE DIAGNOSED

There are a few ways that the cancer can be spotted initially:

- You notice something unusual in your mouth (after your self check, as per guidance on pages 16-17) and have seen a Doctor/Dental Team.
- Your Doctor/Dental Team has noticed something on a physical examination of you.



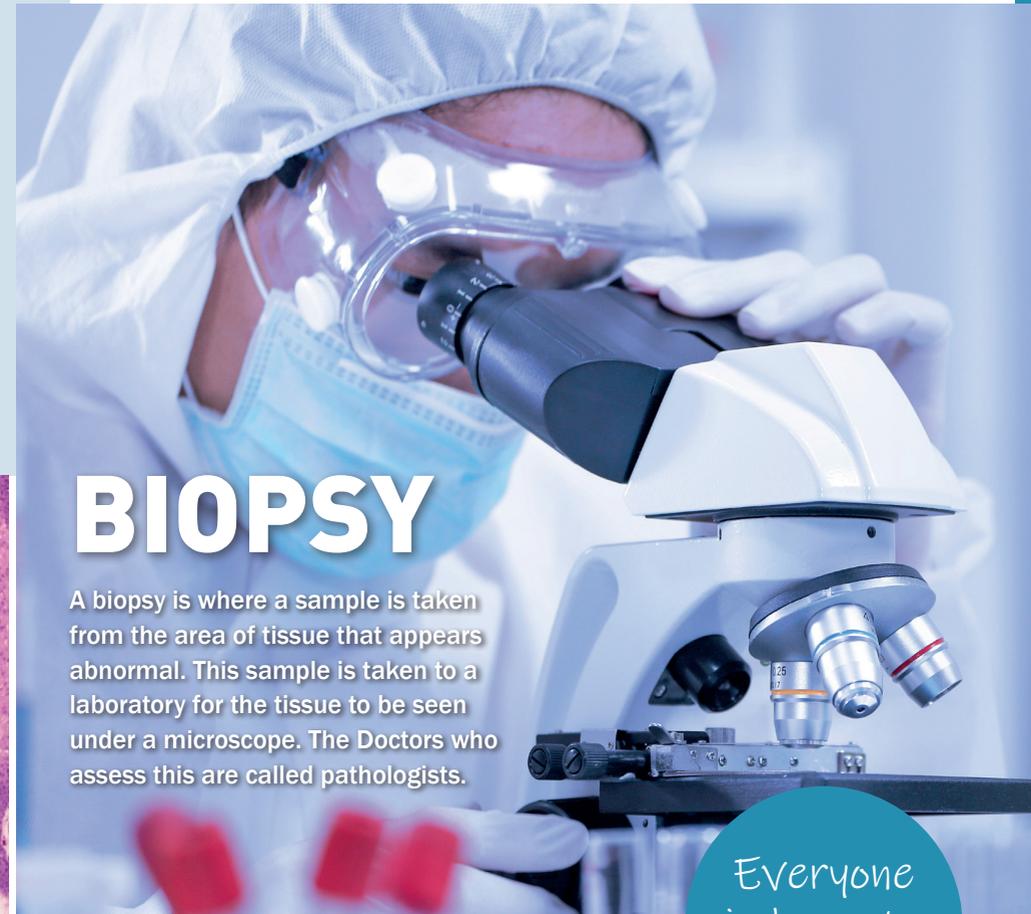
The Doctor/Dental Team would then refer you to be seen by a specialist in Oral and Maxillofacial Surgery (OMFS).

If the Doctor/Dental Team has a high suspicion that it could be a cancer, you would be referred on a '2 week wait' pathway. This means that you

should be seen within 2 weeks so that a Specialist can see and help you quicker if needed.

The Specialists will examine you and if they also feel that there is an abnormal area, they would usually request a biopsy.

"You should be seen within 2 weeks"



BIOPSY

A biopsy is where a sample is taken from the area of tissue that appears abnormal. This sample is taken to a laboratory for the tissue to be seen under a microscope. The Doctors who assess this are called pathologists.

Everyone is here to help you!

The type of biopsy taken will be decided by your Doctor and Oral Maxillofacial Specialist but the process will feel the same for you either way.

The area will be made numb with a local anaesthetic, (similar to when having dental treatment) and a sample will be taken. It should take around 10-15 minutes.

Stitches may be placed, and these will dissolve away after a few days.

Other tests such as blood tests and/or an ultrasound scan of the neck may be required. If so, a fine needle aspiration may be taken at the time of the scan. This is another type of biopsy where some fluid is taken from the neck to be examined under a microscope. This usually causes minimal discomfort.

The Specialists will go through which tests you will need initially and if you have any questions or you do not understand why the tests are being done, please ask! Everyone is here to help you.

It is understandably scary and can be confusing.



NEXT STEPS

After receiving the results of the biopsy, the Oral Maxillofacial Doctors will go through the next steps. Once a cancer is identified, the next step is to find out more about it so that a plan can be tailor made for you. This is called staging and grading.

In order to stage the cancer (find out where it is/where it started, how big it is and whether it has spread), further tests would need to be carried out. These may include some/all of the following:

- Radiographs (X-ray Images)
- CT Scan
- PET CT Scan
- MRI Scan
- Ultrasound Scan
- Further Biopsies

"The Doctor will go over what each scan is and why they would be needed specifically for you."

The grading of the cancer comes from the tissue cells. Under a microscope, the pathologists can help give details about the cell changes and this tells you how fast the cancer is growing.

Both the staging and grading gives information to the Doctors about the cancer and therefore the treatment that you will need.

RESULTS

Waiting for results can make you feel anxious. Results of tests can take from a few days to a few weeks to come back. If you are feeling worried, share your feelings with family, friends, hospital staff and get extra support if you need it. We would often recommend bringing someone with you to appointments.

If the result does unfortunately come back as a cancer, it can feel overwhelming and difficult to process. It is important to remember that the support will immediately be there for you. It will be the start of a journey and you will not be alone.

"We would often recommend bringing someone with you to appointments."





THE TEAM

There will be many people that you will meet who will help support you on your journey.

These will include:

- **Consultant Oral and Maxillofacial Surgeon and their team of doctors**
- **Oncologists (cancer specialist doctors)**
- **Clinical Nurse Specialist**
- **Speech and language therapists**
- **Dieticians**
- **Radiologists**
- **Nurses**
- **Consultant Restorative Dentists**

Everyone is with you during this time and can help answer/direct you to the right people for any questions that you may have. When discussing results and treatment, it can be common to feel overwhelmed and emotional. If you forget to ask something or think of something while at home, the team will give you contact numbers to call for anything you may need. **Your main point of call would normally be the Clinical Nurse Specialist (CNS).**

PREPARING FOR TREATMENT

The treatment will be tailor made for you.

This can involve:

- **Surgery**
- **Radiotherapy**
- **Chemotherapy**
- **Immunotherapy**
- **A combination of a few of the above options.**

In order to decide what treatment is best for you, doctors and health care professionals from different specialties will come together in a meeting called a multi-disciplinary team meeting (MDT) to discuss your test results and your care as a whole.

After this, the doctors will advise you of the outcome and what they feel is best for you.

This is something that you can discuss at length with them if you have any questions.

"Of course, there is always the option of no treatment if you so wish, it is always your decision."



COPING WITH TREATMENT

The treatment journey will usually have ups and downs and a good support system is very useful. Family, friends and the medical team play an important role in your care.

Please speak to someone in your support system if you feel you are not coping with treatment. There is help available if you feel you need it.

PATIENT STORY: STUART CAPLAN

Stuart is a business consultant and lives with his wife, Susan, in London. He was diagnosed with tongue cancer in May 2012 after suffering with a number of symptoms which four of the doctors he consulted failed to diagnose as cancer. His dentist also failed to pick up on his condition.



At that time, he was told that surgery was not an option, and so he commenced chemotherapy in June 2012 followed by radiotherapy. An attempt to install a RIG feeding tube failed so the procedure was attempted a second time. This was abandoned when the radiologist realised that due to his anatomy it would have been impossible to successfully insert the tube. All attempts to complete this procedure were abandoned. This meant that Stuart had to struggle through the radiotherapy which destroyed his ability to eat and drink.

The first chemotherapy drug he was given combined with the fluid in his abdomen

caused by the failed RIG tube insertion caused renal failure. Stuart also underwent intensive radiotherapy. The side effects included severe nausea and various infections one of which attacked his eyes and devoured the skin on his neck and chest. All this meant that he was hospitalised for most of the second half of 2012.

"Now, post-surgery Stuart is active, speaking, eating and drinking."

The four-month post-treatment PET/CT scan showed that although the cancer had not spread, the combined chemotherapy and radiotherapy had failed to destroy it. At this point he was

offered surgery, a glossectomy which could potentially have had a devastating impact on his life. He was therefore referred to a psychiatrist to assess his suitability for this procedure. Prior to surgery Stuart married Susan, his partner of eighteen years. Following a short honeymoon in Paris he had a PEG feeding tube fitted followed by the surgery on 19 February 2013. The ENT surgeon removed two thirds of his tongue and the maxillofacial surgeon built a tongue flap with tissue taken from Stuart's thigh. A neck dissection was also performed to remove lymph nodes.

Now, post-surgery Stuart is active, speaking, eating and drinking. This has involved a lot of hard work and focus but shows the determination to overcome obstacles is typical of him. In addition to his professional career he also does voluntary work for Mouth Cancer Foundation, The Rarer Cancers Foundation, Macmillan, Cancer Voices and as a Patient Representative at London Cancer.

POST TREATMENT

As treatment comes to an end, you will be on the road to recovery. Your doctors will outline what your follow up care will look like. This usually involves regular appointments for them to check the original cancer site and may involve appointments with the Oncologists, Dieticians or Speech and Language Therapists if needed.

As time goes on, you can be seen less often by the doctors. You should be given a person to contact if you have any concerns or questions outside of appointment times. Please ask who this will be. It usually remains as your Clinical Nurse Specialist. There are also support groups to help you; please ask your team for the relevant one for you.

The Doctors, Dieticians and Speech and Language Therapists will have a tailored plan for you to help you on your recovery journey. The aim is to help you return to a new version of normal.

Please let them know if you feel that you are not on track with their plans or need more assistance with your recovery.

You may experience side effects of treatment and it is important that you let your team know as they can help manage this. Some of these side effects can involve changes in the mouth.

The Mouth Cancer Foundation also has a booklet on the Oral Health Care During/After Treatment to help give tips and advice on managing the oral side effects you may experience.

Ask your team for the booklet or find it online on the Mouth Cancer Foundation website.

<https://www.mouthcancerfoundation.org>

KAREN LIESCHING-SCHRODER

TIPS ON BEING PREPARED POST SURGERY



- 1 Knowing you are going to be convalescing in a hospital bed for several days, it is good to get out in the fresh air the day or evening before. The evening before my operation I went out for a run along the seafront with my running club.
- 2 Take a notepad and pen into hospital as you are not sure if you will be able to talk after your operation. Even if you are able to talk, you will find it exhausting, so having a break from this and writing in a pad to communicate is fine. I was told by my surgeon to "use it or lose it" regarding my tongue and talking. Don't overdo it and take the necessary breaks.
- 3 Before going down to the operating theatre, I asked if I could have my mobile phone returned when I came back from surgery. This was really important as it meant I could text loved ones to reassure them; hospital staff were so busy and family and friends had been waiting over 9 hours for news. It helped to be back in touch.
- 4 A friend got me some adult colouring books and pencils. I loved these and found them a welcome distraction and relaxing when feeling stressed. Very therapeutic!
- 5 Look for silver linings to get you through. In hospital mine were - no tracheotomy and no skin graft and I left hospital after 4 days instead of 7. It does not matter how small, one will be lurking somewhere!

THE **2 MINUTE** DO IT YOURSELF SELF-EXAMINATION

THAT COULD SAVE YOUR LIFE!

Examine yourself once a month using our 2 minute self check guide below! All you need is a mirror, a good light source and clean fingers! Follow the step by step guide. At each step you are looking for anything unusual especially any lumps, red or white patches, changes in colour/texture or lingering ulcers. If you are worried ask a friend to check!

01 Face

Look at the whole face - are there any swellings you haven't noticed before? **Inspect your skin** - has anything changed recently? Have moles become larger or started to itch or bleed. **Turn your head from side to side** - this stretches the skin over the muscles making lumps easier to see.



02 Neck

Run your fingers under your jaw and feel along the large muscle either side of neck using the balls of your fingers. Are there any swellings? Does everything feel the same on both sides?

03 Lips

Use your index, middle finger and thumb to feel the inside of your mouth. Pull your upper lip upwards and bottom lip downwards. Look inside for any sores or changes in colour.



04 Gums

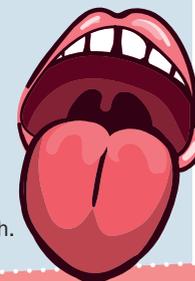
Use your thumb and forefinger. Examine your gums feeling around the gum for anything unusual.

05 Cheeks

Open your mouth and pull your cheeks away, one side at a time, with your finger. Look for any red or white patches. Does everything feel the same on both sides? Use your finger in the cheek to check for ulcers, lumps or tenderness. Repeat on the other side. Your tongue can be helpful to locate sore areas, ulcers or rough patches.

06 Tongue

Gently pull out your tongue and look at one side first and then the other. Look for any swelling, ulcers or change in colour. Examine the underside of your tongue by lifting the tip of your tongue to the roof of your mouth.



07 Floor and Roof of Mouth

Tilt back your head and open your mouth wide to inspect the roof of your mouth. Look to see if there are changes in colour or ulcers. Check for changes in texture with your finger. Lift your tongue up and look underneath at the floor of your mouth. Look for any colour changes that are unusual. Gently press your finger along the floor of your mouth and under your tongue. Feel for any lumps, swellings or ulcers.



SIGNS TO LOOK OUT FOR

Follow up appointments allow your team to monitor your recovery. There is a possibility of infection and other things that require treatment, or that the cancer may have returned.

Check your mouth: Follow the Mouth Cancer Foundation self-check and learn what your mouth normally looks like. Contact your team if you notice any of the following that does not heal or go away in 3 weeks:

- White patch
- Red patch
- Ulcer
- Lump
- Anything new and unusual

Other things to look out for that is not normal for you:

- Unexplained weight loss
- Night sweats
- Fevers
- Change in voice
- Loss or reduced appetite
- Change in swallow
- Ear pain
- Numbness



"It is important to be aware of any changes that you may feel or see and alert your team as soon as possible if you have any worries or concerns."

DENTAL TREATMENT

As soon as you have been diagnosed with head and neck cancer it is essential to undergo a thorough dental examination to check your mouth.

★ TOP TIP

Contact your Dentist as quickly as you can after you've been diagnosed with head and neck cancer to arrange a thorough examination. Tell your Dentist when your cancer treatment is due to start. Ask to book an appointment with the Dental Hygienist if possible.



Improve the health of your mouth

HYGIENE TREATMENTS

The way you look after your mouth during and after your cancer treatment will have a huge impact on your comfort and quality of life. By following simple guidelines you can help prevent the need for significant dental treatment in the future.

At the examination your Dentist will look carefully at every part of your mouth including your gums and your teeth. X-rays and other tests may be carried out.

The aim is not only to discover active dental disease but also to assess whether any other teeth are likely to need significant treatment in the foreseeable future. Treatment for head and neck cancer can result

"The pre-treatment examination forms an essential part of your head and neck cancer journey!"

in making further dental treatment either difficult or in some cases dangerous. It is likely you will be advised to have teeth which have a doubtful future removed. If this is necessary it should be done at least 2 weeks before your cancer treatment begins to allow your mouth sufficient time to heal. Simple fillings and gum treatments should also be done in this time scale.

Treatment for head and neck cancer can result in many changes to the mouth. Your mouth may become very sore during treatment.

It may be difficult to fully open your mouth after treatment and treatments can result in long term dry mouth. This increases your risk for dental treatment and possibly surgical treatment in the future.

Your Dental Team will advise and show you the best way to look after your teeth and gums before, during and after treatment. They will also guide you with ways to reduce your future risk of tooth decay, gum disease and other conditions which may result from radiotherapy, chemotherapy and surgery. Hygienist's will help influence the ongoing health of your mouth.

★ TOP TIP

Visit your Dentist regularly. Carefully follow the advice you are given. Ask your Hygienist about anything to do with your mouth that troubles you. Your Dental Team can provide you with a wealth of information and help.





DENTURES

Ask your dentist to examine your dentures to make sure they fit properly and are not causing any damage to the skin of your mouth. Badly-fitting dentures should be adjusted or replaced before head and neck cancer treatments.

During and after some treatments the skin lining your mouth can become very delicate. Rubbing dentures can cause severe ulceration and even lead to bone damage. Thrush infections are quite common, especially under dentures. Please make sure this is checked before cancer treatments begin.

Check your dentures have no sharp edges or fractures. Keep them as clean as possible before, during and after treatment and ideally leave them out when you go to bed. Comfortable dentures are important for a good quality of life and to preserve the health of your mouth.

★ TOP TIPS

Bring your dentures with you when you attend your pre-treatment dental examination and ask the dentist to check their condition and fit.



Tips from survivor Debbie Weller on looking after your dentures.

- Put water in the sink in case you drop them.
- Use warm water on the dentures before putting them in, so they do not feel so plastic.
- Only use half a tablet twice a week or dentures will fade in the pink bits.
- Clean twice a day with denture toothpaste.
- Use denture cleaning cream/soap and water not toothpaste as abrasives in the toothpaste will scratch the acrylic.
- Rinse or use a saliva lubricant before placing dentures as this may help with retention.
- If using glue, try not to use too much.
- Try to eat evenly with the bite or they will rock and food will get underneath.
- Avoid eating seeds if not glued in.
- Even if you have no teeth attend a Dentist annually to check dentures fit and to check the inside of your mouth, head and neck.

TOOTHBRUSHING

The main question surrounding toothbrushes are; which is best? Electric, sonic or manual? The evidence-based literature recommends electric toothbrushes; however, ease of use is incredibly important. So, it really is personal preference, but whichever you choose please remember to replace them regularly.

A common problem is the infrequent replacement of electric or sonic toothbrush heads or manual toothbrushes. The power gradually declines when the battery is wearing out so keep well charged. The handle will need replacing every 3 to 4 years. Check individual manufacturers for recommendations.

Toothbrushing should include cleaning the gum line as well as cleaning your teeth. If you are unsure on the correct technique for you please ask your dental team for help. Your mouth and gumline may be a little different due to surgery or you may have noticed more recession. A good way of detecting if your toothbrush technique is effective is to use disclosing tablets, available from supermarkets and chemists. Check the instructions



Brush effectively but not too hard!

before use. They are a good visual way of checking where biofilm remains.

Keep an eye on the bristles of your toothbrush. They can easily become soft, bendy

and lose their effectiveness. Toothbrushes and electric toothbrush heads need replacing on average about every 8 to 12 weeks.

★ TOP TIPS

Brush for 2 minutes, twice a day or even 3 times during treatment. Try and brush with your mouth half open rather than wide open, this relaxes your cheek muscles and makes it easier to reach the back. If your mouth is too sore during treatment for tooth brushing please swap to a soft-headed toothbrush. Ask your dental team to help you with options.



TOOTHPASTES

After confirmed diagnosis it is imperative to keep remaining teeth healthy. During treatment the potential for holes to appear in your teeth (tooth decay) is greater due to the amount, type and frequency of both food and drink you will be required to have.

★ TOP TIP

Do not rinse after brushing just spit out the excess as the remaining fluoride will help to keep the enamel and root surfaces resistant to decay.

Prior to diagnosis, brushing your teeth with toothpaste will have been an automatic morning and evening task, it is more important than ever to keep this up and perfect the technique to ensure optimum oral health.

There are a variety of different toothpastes available to suit your needs. You may possibly notice a change in tolerance of different tastes and this may affect the toothpaste you use too. Public Health England Delivering Better Oral Health, an evidence-based document, recommends for patients at a high risk of holes in teeth use a high fluoride prescription toothpaste to be used at least twice per day. Your dental team will also be able to recommend other

toothpastes if you are unable to cope with common mint toothpastes. Other toothpastes available may contain enzymes, vitamin oils, calcium phosphate, ingredients from herbs, or there are even natural toothpaste brand options. Choosing a toothpaste containing fluoride is preferable as it is proven to strengthen teeth.

The root surface area of the tooth presents itself as one of the trickiest areas for head and neck cancer patients to reach. Root decay or root cavities can be found on the exposed parts of the tooth, which are normally covered by the gum. Root surfaces are much softer than the harder top part of the tooth which is called enamel.

GUM HEALTH

Take your time when brushing!

Before your treatment starts we recommend you visit your dental team for an examination and a Hygienist clean. Gum health is checked by your Specialist before treatment.

What is gum disease? You may have heard of the terms gingivitis, periodontal disease or even pyorrhoea. These are all forms of gum disease.

Do your gums bleed? Bleeding gums are often a warning sign of inflammation and gum disease. *Healthy gums do not bleed* is a phrase regularly used, so please do ask your dental team for some help if you are finding that your gums are bleeding. Unfortunately, if you are a smoker you will probably not get this warning sign.



★ TOP TIP

Please do not rush the brushing process. When we have a busy day ahead or if we are feeling low our gum health tends to suffer so please take your time.

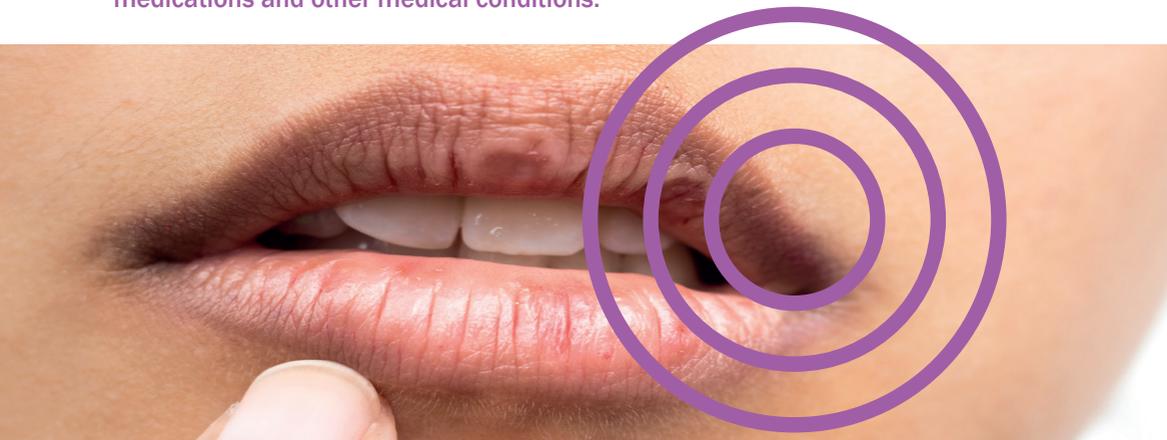
"People commonly tend to avoid their gum line when they find it bleeding"

through a short time where bleeding is present, and this will reduce each day as the plaque is cleaned away effectively.

After surgery you may notice your mouth and teeth are possibly different. If you have had extractions, you will have fewer teeth and so getting used to a different cleaning regime may be needed. Your dental team will be able to help and advise you.

DRY MOUTH

Dry mouth or xerostomia can occur as a result of treatment with chemotherapy and radiotherapy. Unfortunately, it tends to last longer with radiotherapy. Other factors influencing dry mouth include dehydration, medications and other medical conditions.



Dry mouth, also known as xerostomia, is a common side effect of treatments. Unfortunately, with radiotherapy it can be a side effect long term. Other factors influencing dry mouth include dehydration, medications, and other medical conditions.

Saliva plays an important role in the mouth as it not only lubricates the mouth, but it also protects and rebalances the PH levels in the mouth. A lack of saliva can affect speech, the ability to swallow and can give rise to infections such as thrush.

To help ease dry mouth

- Try and stay hydrated.

- Exploring saliva replacements, lubricants and stimulants may also help. Some are available on prescription, and some over the counter. Check the instructions on how to apply to get the full benefit. Products and instructions differ between manufacturers.
- Keep teeth clean. This will reduce the risk of holes in your teeth. Brush regularly with a fluoride toothpaste and do not rinse out afterwards.
- A lesser known, natural medication to promote saliva production is

★ TOP TIP

Try and lubricate your mouth before eating with water or a lubricant. There will be some foods after treatment that you will avoid as eating them will be tricky, please talk with your Specialist team for more help with this.

acupuncture and may be something you wish to consider. Results as to how successful this is varies, but if it is something you wish to consider we recommend speaking with your Specialist first.



TOOTH DECAY

Prior to beginning treatment, we recommend a visit to your dental team for an examination and hygienist for a clean. Any teeth to be restored will need to be treated by your own dental team ideally before your cancer treatment begins.

A treatment plan will be discussed before surgery. If your department has a Restorative Specialist their expertise may also be involved in your rehabilitation plan.

To be able to prevent tooth decay, it is important to understand why it occurs. Tooth decay is the world's biggest preventable disease. Why do we get holes in our teeth? Bacteria naturally grow in the mouth and some types of bacteria intake sugars we eat and convert them into acid. The Stephan Curve (Page 40), shows this. Acid produced dissolves the tooth surface. Regular brushing helps to remove some of these bacteria and saliva contains helpful enzymes that help restore the level of acidity

"To be able to prevent tooth decay, it is important to understand why it occurs."

★ TOP TIPS

Try to keep snacks sugar free if possible and your dental team will advise on options. If your treatment means you are snacking or grazing then please do not worry. Your stamina is more important, and your Specialist team will help should any damage occur during treatment.

and rebalance the mouth. Tooth decay occurs when the frequency of sugars is too often (4 times or more per day), for the saliva to repair the damage.

Before and during treatment your dietitian will encourage you to have frequent foods and drinks with a high sugar content. This is to enable you to be as strong as possible throughout your treatment. Your dental team will advise you on options to help your teeth through this time.



TOOTH EROSION

You may not be aware when tooth erosion is happening. It is becoming a more common problem due to the acid content in foods and drinks.

Your mouth is usually around a neutral pH, which is around 7, however, when we eat acidic foods and drinks the mouth becomes acidic, meaning the pH drops below 7. More importantly when the pH drops below 5.5 this is known as 'the critical pH', and the enamel (hard outer shell covering teeth) softens.

Saliva plays an important natural role in helping to rebalance your mouth and repair any damage caused by acids to the teeth. A lack of saliva which can occur with dehydration, medications, chemotherapy and long term with radiotherapy, raises the risk of tooth erosion. If possible, try to limit acidic foods and drinks to mealtimes.

What does tooth erosion look like? Enamel is the hardest substance in the body and when erosion is detectable the enamel is being dissolved and losing its natural lustre.

Sensitivity can be a sign of erosion as well as the enamel becoming thinner. Damage unfortunately cannot be reversed. Your dental team will monitor and discuss this with you. Please see them regularly. All toothpastes contain abrasives and when used straight after acidic foods, drinks and/or vomiting this can cause further tooth surface loss. Be aware of the potential for tooth erosion if you have fruit for breakfast, our advice is to leave a 40-minute window rather than brushing straight afterwards.

Erosion cannot be avoided but limited if treatment causes regular vomiting. To freshen after vomiting please use a fluoride alcohol free mouthwash rather than brushing with toothpaste. To help protect your teeth use a fluoride toothpaste however leave a 40-minute gap after eating or vomiting before brushing to help the PH of the mouth return to normal.

★ TOP TIP

Try and avoid acidic foods and drinks between meals.

If you are vomiting please do not brush your teeth straight afterwards please use an alcohol-free mouthwash, which contains fluoride. Leave brushing for at least 40 minutes.



Ensure you receive the support you need

ARE YOU A CARER?

A Carer is someone who gives any unpaid help and support to someone with cancer. This includes a partner, family member, friend or neighbour. Everyone's caring situation will be different. Recognising you are a Carer can be an important step in getting the support you need.

Being a Carer for someone can mean:

- Giving emotional support.
- Helping with everyday tasks.
- Driving them to appointments.
- Talking to other people on their behalf, such as health and social care professionals.
- Helping with personal care.

Becoming a carer can be a big change



LIFE AS A CARER

The responsibilities of being a Carer will depend on the needs of the patient. Some responsibilities may be able to be shared or you may find yourself in the position of being a main Carer.

Being a Carer can be rewarding, but the physical and emotional demands can sometimes be difficult to navigate. You may experience a variety of feelings, such as loneliness, sadness, anger and guilt.

Life as a carer can be a juggling act as you may be balancing work, relationships and other commitments as well as being a Carer. If you are caring for a person going through treatment the attention on them, their health and wellbeing will

“Life as a carer can be a juggling act as you may be balancing work, relationships and other commitments”

often be the main focus. It is important that you also have support and someone you can talk to about how you feel and how you are coping.

Becoming a Carer can be a big change in your life. It can take time for you to adjust to the changes. It is important to look after your own well-being and health needs.

As a Carer, you may also need financial support. You may be able to claim Carer's Allowance - www.gov.uk/carers-allowance

HOW YOU MIGHT FEEL

Caring for someone can be fulfilling, but also very challenging. At times you may feel frightened, angry, guilty or lonely. The person with cancer may also have these feelings.



It is not unusual to feel lonely or isolated. Try to meet your needs too, see other people, even if it is just once or twice a week. Accept offers of help to give yourself breaks. Keeping in touch with friends through regular phone calls or social media can help.

As a Carer, you may feel you should be positive for the person you look after. It is hard to remain positive all the time, especially when going through something life changing. It is ok to say if you are feeling tired, worried, depressed or angry and to talk about it.

Talking to other people, whether that is a family member, partner, friend, health professional or counsellor, can help you cope with your feelings. You could also try reaching out to a head and neck cancer support group. Try here for ones closest to you. www.mouthcancerfoundation.org/local-support-groups

★ TOP TIP

The Mouth Cancer Foundation also has a patient and carers helpline number, run by a head and neck cancer survivor, which you can call **01924 950 950**.

TRACEY NOONS' TIPS ON WHY

FINDING SUPPORT IS KEY



Each day we seek support from our family and friends without a second thought, a quick call here, a text there, possibly even a daily tea break; potentially even with cake. My point is our friends and family are always there for us, a constant; providing you found yourself some good friends.

Everyone on the mouth cancer journey experiences different challenges, but a common comment from patients the Mouth Cancer Foundation has spoken to is they have all benefitted from great support around them.

Support may very well be from friends and family, but support can also come in the form of seeking out support groups, a place where people are able to come together and talk about similar experiences.

Support may also come from helplines, who provide a friendly and informative experience listening to your needs, concerns and being a friend at the end of the phone.

To find a support group near you visit www.mouthcancerfoundation.org/local-support-groups

Support group attendee, Tracey Noon has some top tips on why finding support is important.

- 1 The support group offers space to talk about things friends and family don't know about and it feels great to be in an environment where PEGS and high calorie diets are normalised.
- 2 It is great to be chatting to people who have similar experiences to me.
- 3 Finding support frees that weight off my chest... Once I talk about my concerns and worries it is as if they disappear.
- 4 I know I am not alone in my journey.

"It is great to be chatting to people who have similar experiences to me."



LOOK AFTER YOURSELF

Many people think being a Carer means you should ignore your own feelings and only think about the needs of the person you are caring for. In reality you both need support to help you cope. Being honest about your feelings can help you feel less stressed and more in control.

Try to get the support and information you need early on to help you develop ways of coping. Talk to family members, friends or one of the health or social care professionals involved. If you start to feel overwhelmed or depressed it is important to get professional help.

★ TOP TIPS

As a Carer, it is important to look after yourself. Here are some things to do to take care of you:

- Take a few minutes every day to do something for yourself. Go for a short walk, read a magazine, sit down and finish a whole cup of tea.
- Tell your GP you are a Carer so they can give you support and advice.
- Keep any health appointments you have booked in, such as any screening appointments.
- Check if you can get a free flu vaccination – you might be able to have one if you are the main carer.
- It is ok to not be ok. Speak up if you experience any problems, finding it hard to cope, struggling with eating or sleeping. There are professionals out there who can help you.
- Self care is important too. It is ok to take a few days out to do something for you and look after yourself.

CARERS STORY: TIM PARSONS

I am a Firefighter by profession. People tend to think that Firefighters save lives, that they are 'brave heroes', but I didn't feel very brave when I got the dreaded phone call from my wife, Rachel, that August afternoon in 2008, when she said, "I've got Cancer".



Nothing can prepare you for being on the end of that phone call. In those few seconds, my life fell apart. All our plans for the future disappeared in an instant. I thought Rachel was going to die, and that I would be left

bringing up our five small children single-handed. Our youngest child at the time was only two years old. As Firefighters, we find people at a low point in their lives, and we make it better for them.

This was something I couldn't fix. I didn't know how or where to start to make it better for Rachel. So, I did what I knew how to do. Be strong. Be a man. Be the Firefighter. I clicked into work mode – tried to rationalise, prioritise, and treat life like an incident. The problem was things weren't normal – nor would they ever be again. In the months following Rachel's operation, I tried to hold things together – looking after Rachel, our children, work, and normality. I went to my Occupational Health Department at work for support, who told me I was entitled to one day off to look after Rachel. It was so hard. We didn't talk to each other about how we felt. We avoided our emotions for 3 months until our world began spinning out of control. Rachel thought I didn't care.

I practically had a breakdown, and was given sick leave from work. Through the support of the Firefighters Charity, we managed to get some time alone to rest and recuperate, just the two of us. We shared



our feelings. Our commitment to each other and our love was renewed. We began the process of rebuilding the life that was shattered by cancer.

Now, life is so much richer than before. Our love is deeper, we cherish time with family, and we seize each day given to us. Today, life is good – and tomorrow is another day. We will forever live in the shadow of cancer. We know that every pain, ulcer, or fatigue brings worry and fear, but humour keeps us from dwelling on the fear. We still laugh about my fainting when they took the dressing off Rachel's arm in hospital. I was known for a long time by the nurses about being the Firefighter that they saved after that!!!

"Our love is deeper, we cherish time with family, and we seize each day given to us. Today life is good - and tomorrow is another day"

For me, the lifesavers are all of those who work towards mitigating the damage caused by this dreadful disease: the Surgeons, Doctors, Dentists, Hygienists and their colleagues and team members. Those who strive to educate the public about the dangers of mouth and head and neck cancer. They save lives through their work and are truly there for people in their darkest hours. And to those who survived mouth cancer, and bear their scars with courage and fortitude and dignity – they are the bravest of the brave.

And amongst them of course, there is my own particular hero – my Wife and mouth cancer survivor – Rachel Parsons.

FATIGUE AND THE SPOONS THEORY

Fatigue can be a noticeable side effect of treatment. If you are a person who is always on the go, it may be difficult to adjust post treatment.

There is light at the end of the tunnel though and slowly life will readjust. Give yourself time, allow yourself to sit down and do nothing today. It is ok to not be ok.

“The Spoons Theory” is a simple metaphor for fatigue created by a lady called Christine Miserandino who was explaining her lupus fatigue to her friend in a restaurant.

“So, imagine a regular day before treatment, and you attach a spoon to each activity; getting out of bed, going to the bathroom, brushing your teeth,

having a shower, getting dried and then dressed and so on. Now, imagine you use a spoon for each of these activities throughout the day. You will certainly use up many spoons.

As a person before treatment you will have infinite spoons however after treatment you may only have, for example 30 spoons for the day. It is easy to see how you may run out of spoons or have to make choices. Remember to always leave a spare spoon for the following day. Be aware of borrowing spoons from the following day too.

It is important to think about your day ahead. Some days you will have more spoons than others, but remember to leave some spare”.

The hardest thing is to turn down or reschedule different activities as you run out of spoons. Adjustments will need to be made to ensure maximum recovery.

Physical activity is recommended even if it is managing the stairs, or going for a short walk. It is important to try to do something. Your specialist team will help you with this.

SPEECH CHANGES

The most common speech change before and after mouth cancer treatment is known as dysarthria (dis-arth-ria). This is where speech sounds are slurred or imprecise.

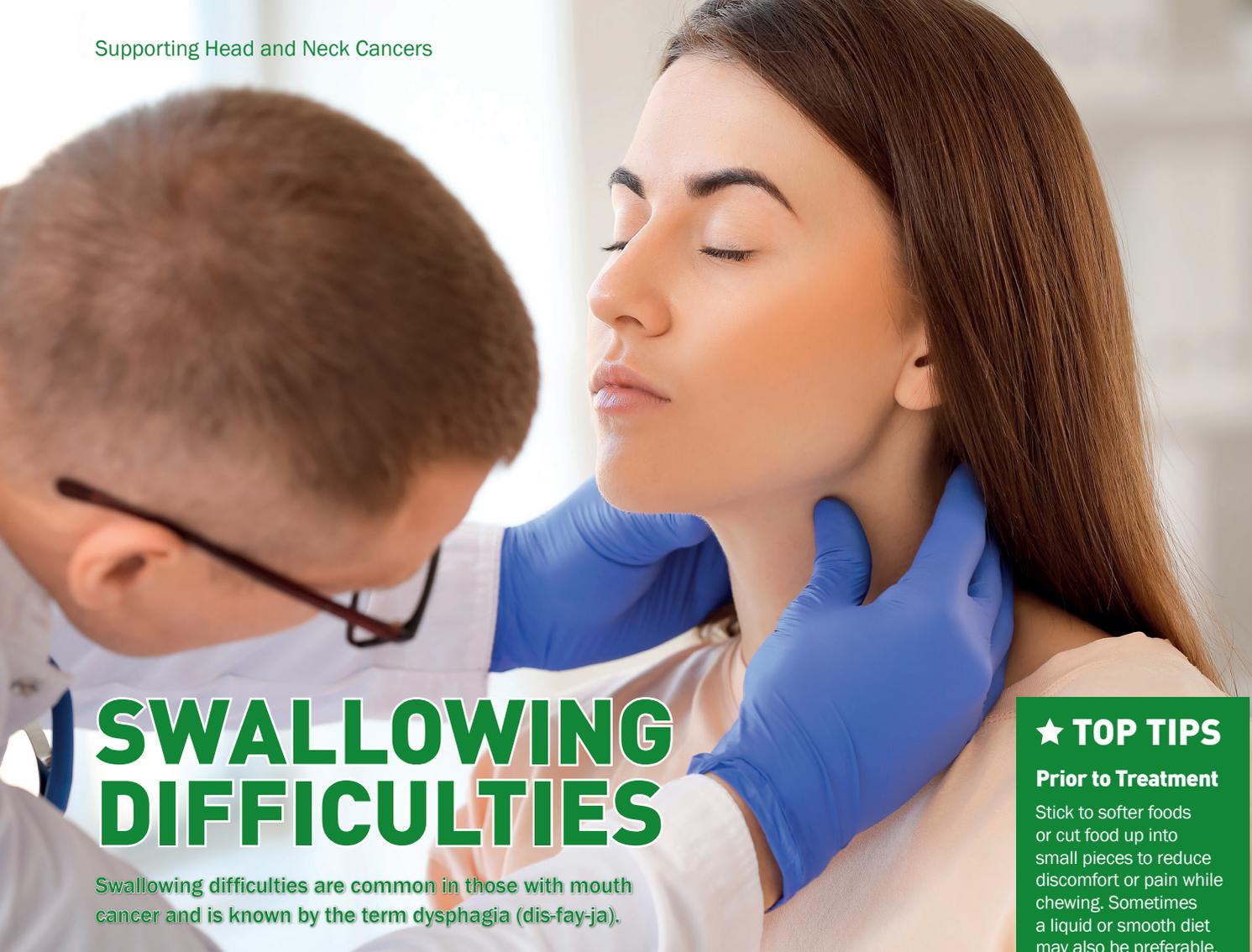
Speech can be affected prior to treatment more often in those with tongue cancers due to pain and/or the location of the tumour on the tongue. After treatment many more people with different tumour sites will have at least transient difficulties with their speech due to anatomical changes, pain and swelling.

Some people with soft palate cancers will also be affected by changes to how nasal their speech sounds after treatment. Speech Therapy is usually provided after treatment. Speech changes may persist or develop after treatment and you will be assessed by your speech and language therapist who will provide you with exercises and/or strategies to maximise your return to clear speech.

Top tips during treatment:

- Try to speak more slowly and over-articulate to help others understand you.
- Keep a method of writing handy during your treatment so you always have a way of communicating e.g. paper/pen, mobile phone, text-to-speech app.





SWALLOWING DIFFICULTIES

Swallowing difficulties are common in those with mouth cancer and is known by the term dysphagia (dis-fay-ja).

Prior to and after treatment it is possible you will have difficulties with chewing as a result of pain or discomfort and may require changes to the textures of foods you eat.

This may be temporary or more permanent depending on your treatment. For some people difficulties with

swallowing safely is also a problem. Your Speech and Language Therapist will be able to assess your swallowing needs throughout your journey and provide advice on any changes required to help manage your swallowing difficulties. They work closely with your Dietician to ensure you are

able to maintain your weight throughout your treatment and rehabilitate your swallowing as close to normal as possible.

Changes to your anatomy and dentition are taken into consideration when you are counselled on longer term rehabilitation.

★ TOP TIPS

Prior to Treatment

Stick to softer foods or cut food up into small pieces to reduce discomfort or pain while chewing. Sometimes a liquid or smooth diet may also be preferable. Your dietician may also recommend other additions to your diet to help you with calorie intake.

After Treatment

Timing your pain relief with meal times can help you eat and drink as normally as possible sooner.

TRISMUS



Trismus is the term used to describe a reduction in mouth opening. This can happen at any time in your treatment pathway with mouth cancer due to several reasons such as pain, tumour growth, anatomy changes post surgery, and tissue changes after radiation.

It's important to have your jaw opening assessed by your Doctor and Speech and Language Therapist to develop a trismus therapy program for you at an appropriate time. There are both exercises and passive jaw range of motion

devices which you may be offered and need to use long term. Good mouth opening is important for functions such as speech and swallowing, as well as maintaining good oral hygiene and monitoring of your cancer site.

★ TOP TIP

Monitor your jaw opening using 3 stacked fingers between your front teeth - 3 fingers is average, 2 or less indicates an issue with jaw opening.

Let your team know if you develop changes to jaw opening including pain.



NUTRITION AND WHAT TO EAT

It is important to eat the right foods and maintain a healthy weight, as this will help you increase your strength, fight and recover from infections, surgery or illness.

To do this it is important you consume enough calories, before during and after treatment. If you are having difficulty with pain or swallowing, you may also find it easier to have foods that are softer or more pureed in texture.

Choosing softer foods or fluids that contain a high amount of calories is a great way of maintaining a good nutritional intake. Protein is a key component of muscle tissue and our requirements of protein go up if we have large areas of tissue to heal or if we are fighting an infection.

"If your appetite is poor, we would encourage you to eat smaller amounts more frequently."

This is an easy way to enrich the foods if you are currently eating, with calories and protein, without having to significantly increase the quantity you eat.

If your appetite is poor, or you are using less than 1 pint of whole milk a day you may like to "fortify" by adding 4 tablespoons (50g) of whole milk powder to a pint of whole milk

- Use whole milk or 'fortified' whole milk in all drinks, to make porridge, on your breakfast cereals and when cooking puddings.
- Add cream to soups, breakfast cereals, puddings, milkshakes, pasta sauces.
- Add grated cheese to soups, pasta and cooked vegetables.
- Add jam, sugar or honey to porridge or smoothies and milkshakes.
- Add butter, margarine or oils to cooked vegetables, potatoes and rice.
- Use salad cream, mayonnaise and cream cheese on sandwiches and baked potatoes.
- Add ice cream or creamy Greek yoghurt to milkshakes.
- Spread butter and margarine thicker on bread, toast, scones, muffins or chapattis.

Adequate calories will ensure that your body does not breakdown muscle and fat for energy as this will lead to weight loss, which will increase your risk of infections and lengthens recovery time from illness and surgery.

If your appetite is poor, we would encourage you to eat smaller amounts more frequently. There are no foods that you will be obligated to avoid but you may find that you are more sensitive to foods containing high amounts of salt, citrus or spice and subsequently, these may cause burning or oral discomfort so you may choose to avoid them.

If you continue to struggle to eat and drink, even after trying the tips above, you can be referred to a specialist dietitian who will be able to prescribe additional nutritional supplementation to help improve your calorie intake. They, together with the oncology team will be able to discuss additional nutrition support that is available.

Favourite Post Surgery Snack from Debbie Weller

Scrambled eggs with cream on bread – wait until the egg with cream has made the bread soggy and it should slide right down!

And Tracey Noon

Frozen yoghurt.

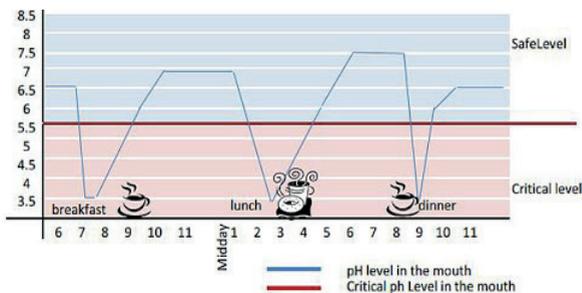


WHEN TO EAT SUGAR

Now, we are not going to tell you to cut out sugar completely, but we are going to try and influence when you eat it.

Sugar is all around us hiding in the most peculiar places, (bread), or staring us straight in the eye, (chocolate) meaning that it is growing increasingly difficult to cut it down...but we have you covered.

Below is an example of a healthy Stephan's Curve graph. It highlights a person who has kept their sugar intake to meal times.



"Stephan's Curve was developed by a Robert Stephan in 1943 in an effort to better explain to the nation when to eat sugar and how much of an impact it can have on your oral health."

By limiting sugar intake to around meal times your mouth spends less time at a low pH level meaning your teeth are less likely to start dissolving! The graphs show that by consuming sugar throughout the day, the mouth enters a critical PH level almost twice as many times.

There is only one exception to this rule, and that is, whilst having treatment sugar plays an important part in ensuring you are getting the correct number of calories. Therefore, we advise you to do what is best for your journey.

Favourite Post Surgery Snack from Karen Liesching-Schroder

Rice pudding.

NATURAL SUBSTITUTES TO SUGAR

Sugar is extremely important for patients who are going through their mouth cancer journey. Its calorific content definitely over takes any oral health concerns which is a great news for those of you who have a sweet tooth!

If you are looking for a natural alternative be sure to check these out:

Xylitol, Manuka Honey and Stevia

Adding sugar into meals is also a great way to add calories into your diet; popping it on top of your porridge in the morning, mixing it into bananas or even adding it to yoghurt.

Be sure to check out Stephan's Curve on page 40 for a more in-depth explanation of when to eat Sugar after your active treatment is completed.

Favourite Post Surgery Snack from Graeme LLOYD

Orange Juice with LOTS of ice and porridge with sugar and mashed banana.





SMOKING

Worldwide smoking is the single most important public health problem, so if you do smoke it might be the time to think about cutting back or quitting altogether.

The NHS offers some top tips on giving up. www.nhs.uk/live-well/quit-smoking/10-self-help-tips-to-stop-smoking/

- Think positive.
- Make a plan to quit smoking.
- Consider your diet.
- Change your drink.
- Identify when you crave cigarettes.
- Get some stop smoking support.
- Get moving.
- Make non-smoking friends
- Keep your hands busy
- Make a list of reasons to quit.

The detrimental effects of smoking and tobacco use on oral health are well recognized. Oral cancers and pre-cancers, periodontal diseases and poor wound healing are the most significant and serious effects of smoking on the mouth. In addition, staining of the teeth, soft tissue changes and halitosis are aesthetic and social impacts of smoking directly related to oral health.

Smoking is the largest single preventable cause of death and disability in the UK. Each year smoking kills 120,000 people, amounting to one in five of all deaths.

The largest single preventable cause of death

Millions of otherwise apparently healthy smokers visit a dentist every year for a check-up or dental treatment.

Members of the dental team can therefore play a major role in helping people give up smoking by referring smokers wanting to quit to their local service.

ALCOHOL

If you want to stop drinking alcohol as part of a move towards a healthier lifestyle, cutting down on the amount of alcohol you drink as opposed to giving up alcohol completely will bring lots of health benefits, and can be easier to stick to.



Reducing the amount you drink can also be a positive stepping stone to giving up alcohol completely in the future.

Cutting down doesn't have to be complicated. If you drink every night, start by designating a couple of days a week as alcohol free days. Official alcohol unit guidance is that it is safest for both men and women to not regularly drink more than 14 units a week and to spread them out evenly over the week. Drinkaware has plenty of tips for cutting down on alcohol. www.drinkaware.co.uk

30% of people with mouth cancer drink excessively. Excessive drinking means more than 21 units of alcohol

per week. That's about 7 large glasses of wine or 11 cans of medium-strength lager.

Alcohol Works In The Following Ways:

- Dries out the skin of the mouth and makes it more porous.
- It is broken down by bacteria in the mouth to make cancer-causing chemicals.
- Breaks down within the body to produce chemicals which are poisonous to cells and damage their DNA.
- Many people who drink large amounts of alcohol neglect to eat properly. Poor diet is also a risk factor for mouth cancer.

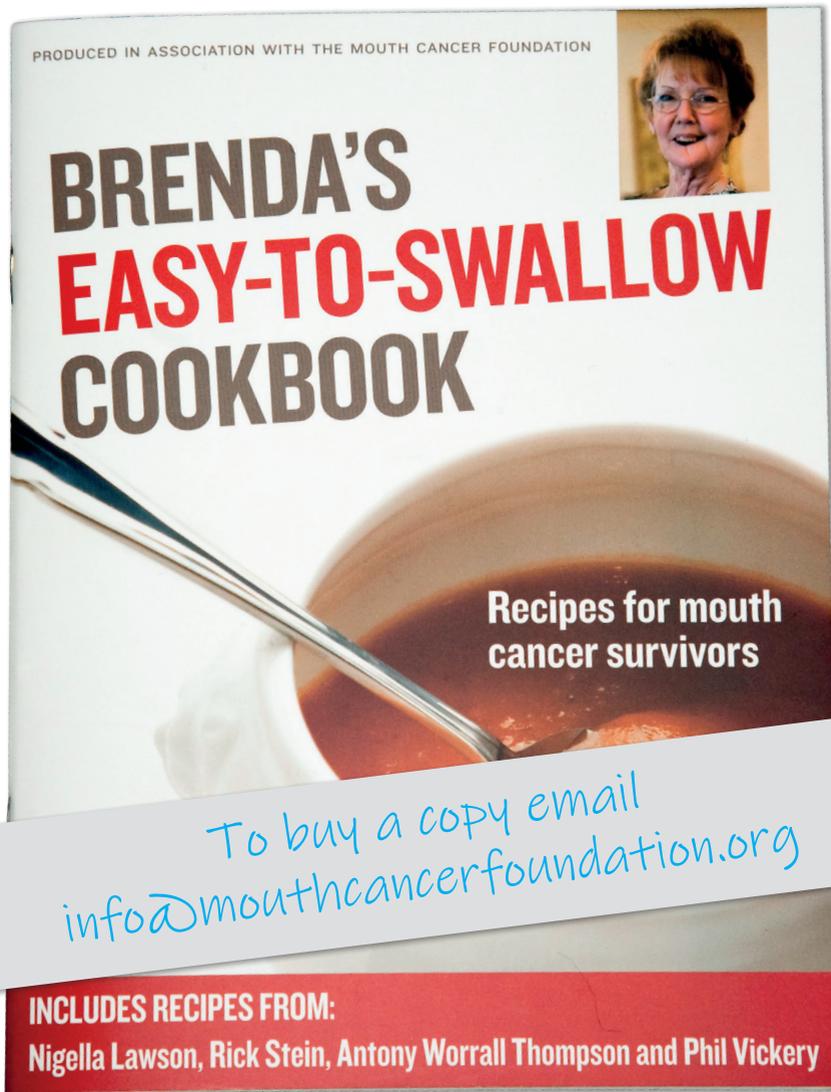
★ FACT

Drinking alcohol and smoking at the same time increases the risk of mouth cancer about 30 times. This is because alcohol affects the skin of the mouth allowing tobacco toxins to pass through more easily.

Tobacco smoke contains formaldehyde, a poisonous chemical similar to acetaldehyde produced by the breakdown of alcohol.

These two chemicals together can overwhelm the body's defence mechanisms.





To buy a copy email info@mouthcancerfoundation.org



KEEPING ACTIVE DURING TREATMENT & BEYOND

Contact your medical team prior to any exercise regime

Keeping active offers great benefits for both the body and the mind. The Mouth Cancer Foundation strongly recommends doing something physical once a day. This could be walking up the stairs, around the block or simply around the garden.



Nobody is expecting you to sign up to next year's half marathon, but do keep those endorphins flowing as they are important for your mental health. Remember that time your arm was aching baking your favourite cake? Remember the washing basket seemed like a lead weight, but you carried it, and lifted all the clothes out one by one? You were moving and it is all good for you. If you have previously been a very active person, there

is a chance that your fitness will decline, and while we strongly endorse a form of exercise please do not push your body to the maximum. That time will come but, now may not be the right time. There may be days activity feels like too much and it is important to listen to your body and know when to rest. Do what is right for you and your body. Everybody's body is different. We all only have one body and need to look after it.

- Here are some simple exercises to think about...**
- Hoola Hooping.
 - Dancing to your favourite song on the radio.
 - Walking to the coffee shop.
 - Use water bottles or tins as weights to keep muscles toned - You can even do this sitting down.
 - Watching your favourite TV programme, recognising its too much for your body today - that is perfectly fine!

"Exercise is hidden away in lots of different tasks."



FREE 10 KM

IN AID OF
MOUTH CANCER
FOUNDATIONCREATE A ROUTE, AROUND YOUR LOCAL
AREA, WITH A TOTAL DISTANCE OF 10 KMTHIS COULD BE ANY COMBINATION SUCH AS 1 X 10 KM, 2 X 5 KM, 10 X 1 KM
THE ROUTE CAN BE DONE IN ONE GO, OR OVER SEVERAL DAYSVisit our website for more information or email
info@mouthcancerwalk.org
or alternatively call us on 020 8940 5680Mouth Cancer Walk
www.mouthcancerwalk.org

FACTS ABOUT MOUTH CANCER

1 person every 3 HOURS is lost to Mouth cancer

Over 8700 new cases in the UK each year

Each year 2700 + lives are lost to Mouth Cancer

Worldwide Mouth Cancer affects 650,000 per year

Mouth Cancer is TWICE as common in men

78% of cases occur in the Over 55 age group

Incidence has risen by 49% over the past 10 years

5 year SURVIVAL rate has hardly improved in last few decades





PARTNER & INTIMACY ISSUES

by leading Psychologist and Relationship Expert Jo Hemmings

A diagnosis of head and neck cancer can be physically and emotionally debilitating in itself. It can have a profound effect on psychological and psychosocial well-being and quality of life. And in particular this can affect resuming intimate relations with your partner.

As many as 50% of all patients treated for head and neck cancers, report decreased libido and decreased sexual enjoyment. Depression, fatigue, poor body image and anxiety are the main contributory factors. Additionally, the dry mouth symptoms that develop after radiation also make many patients not feel like being intimate, using their mouths to kiss or any other

form of oral stimulation. Radiation can also impact on the pituitary gland, reducing its function, again leading to physical issues with sexual performance.

All these reactions are perfectly normal and while over 70% of patients don't report these symptoms to their GP or consultant, it is important to share them as there are so many ways in which they will

understand – without any embarrassment – and can help you to resume a fulfilling and intimate relationship with your partner. For example, if there are pituitary gland issues – which may lead to loss of sex drive, change in menstrual cycles, hot flushes, vaginal dryness and erectile dysfunction – this can be identified with a simple blood test.

“As many as 50% of all patients treated for head and neck cancers report decreased libido and decreased sexual enjoyment.”

Your doctor is best placed to help with physiological treatments – simple but effective medications for dry mouth or an oestrogen cream for vaginal dryness for example – but they can also refer you to a number of appropriate psychological counsellors or sex therapists, to help with your emotional concerns about becoming intimate again.

MASK ART

Our Charity Project Award winners from 2019, Mask Art, developed a creative way of helping patients through their radiotherapy treatment. The charity based at Sheffield University encouraged patients struggling with treatment to get artsy with their masks.

Some masks embodied clowns, theatrical characters or took on the features of buildings, it is completely dependent upon the artist/patient's interpretation. Transforming the mask into something that the patients valued and connected with took away a lot of the fear for patients going through treatment; some even kept their masks.

The process involves using paper mâché over the outside of the mask, creating different layers and then using paint to transform the mask into something very personal.

“The charity encouraged patients struggling with treatment to get artsy with their masks.”

Why not have a go yourself and get creative



WORK WORRIES

From the offset of your diagnosis you are automatically protected by the Equality Act 2010 if you live in England, Scotland or Wales. If you live in Northern Ireland the Disability Discrimination Act 1995 outlines your rights.



Employers must make reasonable adjustments to your working schedule (allowing time off for appointments) and job description to enable you to comfortably work within your ability and most importantly manage your health.

Both Acts protect against discrimination within the workplace.

Examples of this are:

- Employers implying it is better if you retire or stop working.
- Demotion.
- Leave you with difficulty accessing your sick pay.
- Hand out warnings for excessive sick leave and not taking your cancer diagnosis into account.

If you are self-employed, it may be that you are able to continue to work throughout your treatment but at a reduced capacity.

Telling Your Employer, You Have Cancer

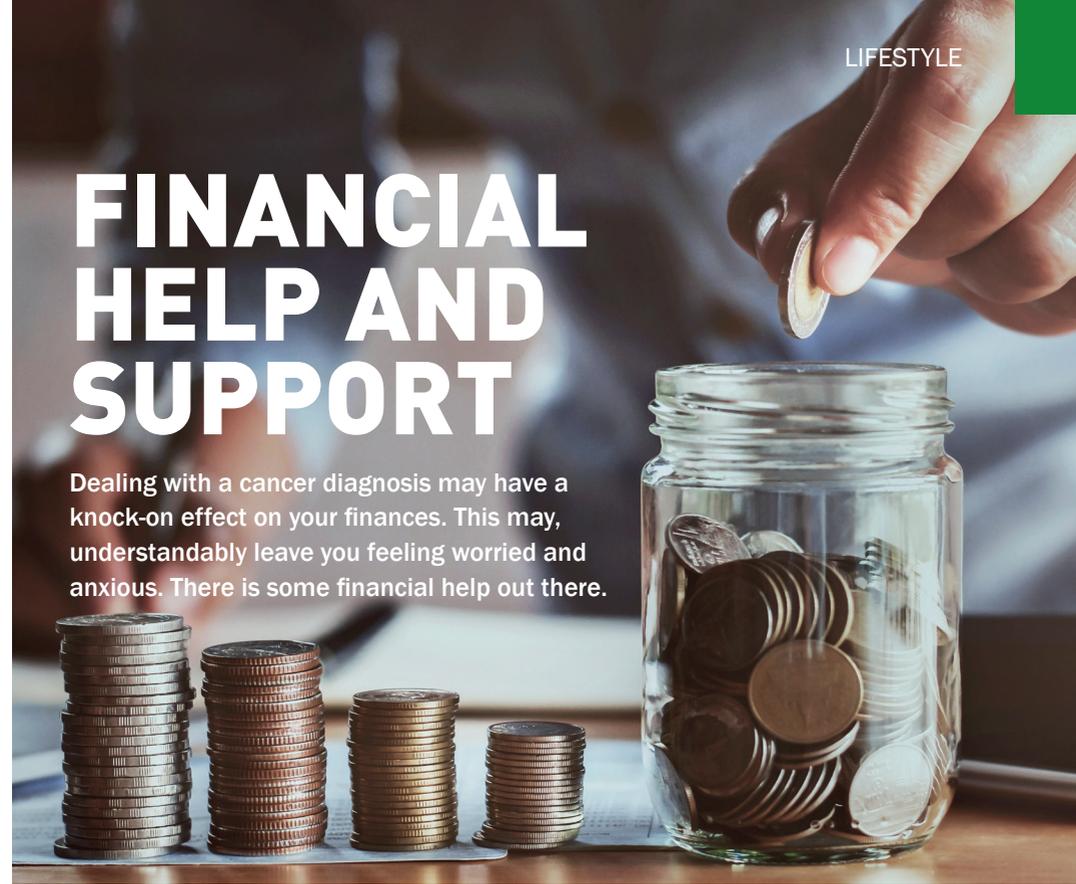
Telling an employer about your new diagnosis is something very personal, and the amount of information which you disclose is completely up to you. Here are some steps you may wish to take...

1. Request a private meeting with your boss.
2. Making someone in the HR department aware.
3. Telling a trusted co-worker – This is completely up to you but having a friend inside your working environment who can be a constant and a place for support could be very valuable to your journey.
4. Plan how to share your information.
5. Plan how much information you are willing to disclose.
6. Be open to accept help.

If you are a carer and concerned about work related issues, unfortunately the employment law surrounding the Equality Act 2010, and the Disability Discrimination Act 1995 is complex. We suggest you seek further advice from the Citizens Advice Bureau, ACAS or the Equality Advisory and Support Service.

FINANCIAL HELP AND SUPPORT

Dealing with a cancer diagnosis may have a knock-on effect on your finances. This may, understandably leave you feeling worried and anxious. There is some financial help out there.



The government currently offer a multitude of different benefit options, some of which are outlined below.

- Income tax refund.
- Job seekers allowance.
- Universal credit.
- Employment and support allowance.

Disability benefit

- Personal independence payment.
- Disability living allowance for adults.
- Attendance allowance.

Pension benefit

- State pension.
- Pension credit.

Bill and housing costs

- Universal credit and housing benefit.
- Help with council tax and/or rates.
- Mortgage interest rates.

Carers benefits

- Bereavement benefits.
- Carers allowance & credit.

Recognising that finances could be disrupted is a huge step and not something to worry about. Each option listed above is there to help and alleviate any pressure.

Citizens Advice are also a great place to look if you are trying to find financial advice:

Adviceline

England: 03444 111 444
Wales: 03444 77 20 20
Textphone: 18001 03444 111 445

For more information please visit-
www.cancerresearchuk.org/about-cancer/coping/practically/financial-support



RESOURCES LIST A-Z

The following organisations offer a wealth of information and support:

ACAS

www.acas.org.uk

Access to Work

www.gov.uk/access-to-work

Cancer Research UK

www.cancerresearchuk.org

Carer's Allowance

www.gov.uk/carers-allowance

Citizen's Advice Bureau

<https://www.citizensadvice.org.uk>

Disability Discrimination Act 1995

www.legislation.gov.uk/ukpga/1995

Drinkaware

www.drinkaware.co.uk

Equality Act 2010

www.gov.uk/guidance/equality-act-2010-guidance

Equality Advisory and Support Service

www.equalityadvisoryservice.com

Financial Assistance

www.cancerresearchuk.org/about-cancer/coping/practically/financial-support

Head and Neck Cancer Foundation

www.hncf.org.uk

Macmillan Cancer Support

www.macmillan.org.uk

Mouth Cancer Foundation

www.mouthcancerfoundation.org
www.mouthcancerwalk.org

NHS

www.nhs.uk

Oral Health Foundation

www.dentalhealth.org

Psychologist

www.johemings.co.uk

Smoking

www.nhs.uk/live-well/quit-smoking

The Swallows Head and Neck Cancer Charity

www.theswallows.org.uk

Working with Cancer

www.workingwithcancer.co.uk

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www.irwinmitchell.com

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Graeme Lloyd
Patient



Tripat Mahajan
Dentist Clinical Ambassador



Tracey Noon
Patient



Rachel Parsons
Patient Ambassador



Tim Parsons
Carer Peoples' Ambassador



Debbie Weller
Patient



MOUTH CANCER FOUNDATION

Did you find this handbook useful?

Email info@mouthcancerfoundation.org for our full range of publications

The Mouth Cancer Foundation is a leading UK head and neck cancer charity dedicated to raising awareness, promoting early detection of mouth cancer and supporting those affected by it.

We promote the early detection of mouth cancer through informing the public about the signs, symptoms, facts, figures and key causes of mouth cancer. As well as providing assistance and information on living with mouth cancer for families, friends and carers.

Proud pioneers of a self-examination for the general public, to easily check for mouth cancer and tirelessly working to educate the Dental profession to carry out thorough head and neck cancer checks at routine patient appointments.

The charity is working to change peoples' perception of the disease one step at a time through the Mouth Cancer 10 KM Awareness Walk – the only one in the world!

We are fortunate to have Ambassadors who are experts in their respective fields. They support our organisation as well as spending their time raising awareness and educating the dental and medical professions and the general public about all head and neck cancers.

"We promote the early detection of mouth cancer through informing the public about the signs, symptoms, facts, figures and key causes of mouth cancer."



Saving Voices

Our mission is to save the voices of mouth, throat, head and neck cancer patients at risk of losing them due to surgery or treatment and give back the power of speech in our latest initiative.

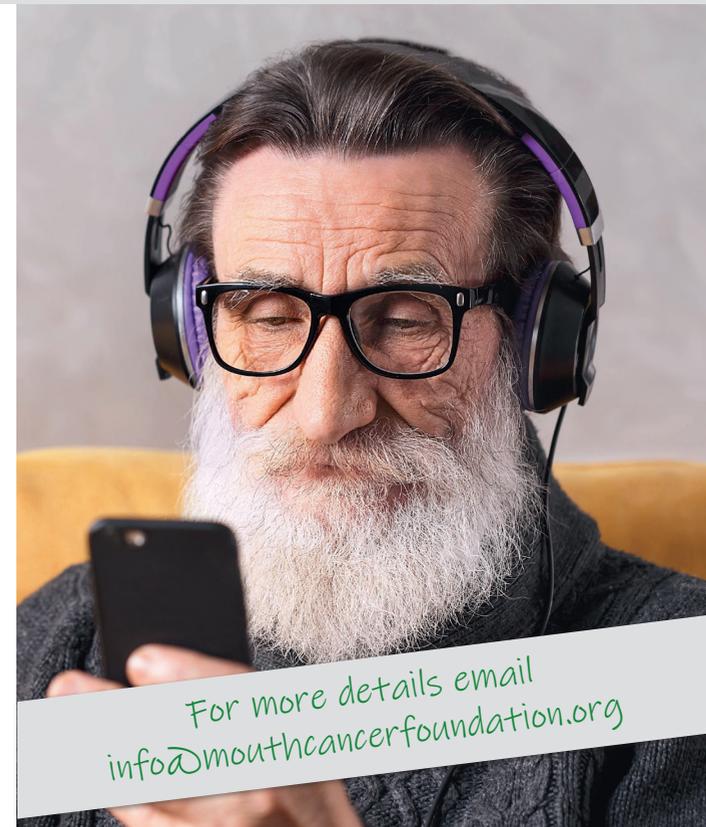
Help us to help you improve the quality of your life

The Mouth Cancer Foundation will become the go to charity for patients wishing to bank their voices through a **£1500 per person** Saving Voices Grant

(Subject to approved criteria, terms and conditions).

With the aid of modern technology, voice preservation enables individuals to communicate in a voice that reflects their unique identity. Working with a voice banking platform, the user can bank their voice by recording 2 hours' worth of sentences. These speech recordings will be used to create a personalised digital voice. The user can then type messages that are converted to speech that sounds like the patient's original voice.

All you need is a computer, headset microphone, which the charity will provide, 1,500 Sentences = 2 hours of recording time and someone to support and motivate you. We appreciate this will be happening at a time you may be preparing for surgery. Once the voice is built, it can be used via a communication app.



For more details email info@mouthcancerfoundation.org



Facts about MOUTH CANCER

The **2 minute** do it yourself self-examination that could save your life!

Check yourself once a month using your simple **2 minute self check guide**.

EARLY DETECTOR IS KEY!

What is Mouth Cancer?

This is the prevention plan for the early stages of mouth cancer. It shows you the signs, symptoms, and risk factors of mouth cancer. It also shows you how to check yourself for mouth cancer.

Symptoms

- A lump or swelling in the mouth
- A sore that does not heal
- A change in the way you talk
- A change in the way you swallow
- A change in the way you breathe
- A change in the way you taste
- A change in the way you smell
- A change in the way you feel
- A change in the way you look
- A change in the way you act
- A change in the way you think
- A change in the way you feel about yourself
- A change in the way you feel about others
- A change in the way you feel about life
- A change in the way you feel about death

Risk Factors

- Smoking
- Drinking alcohol
- Eating a diet high in fat and low in fruit and vegetables
- Having a long-term condition such as reflux
- Having a long-term condition such as diabetes
- Having a long-term condition such as high blood pressure
- Having a long-term condition such as heart disease
- Having a long-term condition such as kidney disease
- Having a long-term condition such as liver disease
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www.mouthcancerfoundation.org

Facts about MOUTH CANCER

What is HPV?

Human papillomavirus (HPV) is a common virus that is spread through intimate contact. Most infections are brought on by the body's immune system and do not cause any symptoms.

HPV is a common infection affecting 80% of people at some point in their lives.

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MOUTH CANCER Self Check

The **2 minute** do it yourself self-examination that could save your life!

01 Face

02 Eyes

03 Ears

04 Tongue

05 Throat and Roof of Mouth

06 Risk

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Facts About Mouth Cancer

- 5 times more likely to die
- £900 per week in extra care costs
- 650,000 people in the UK have mouth cancer
- 1 in 10 people over 55 will get it

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MOUTH CANCER Self Check

Are you checking for Mouth Cancer once a month?

www.mouthcancerfoundation.org

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To order copies of our leaflets and posters visit www.mouthcancerfoundation.org/get-involved/merchandise

FREE 10 KM

Walk from Home

1st October to 30th November 2021

CREATE A ROUTE, AROUND YOUR LOCAL AREA, WITH A TOTAL DISTANCE OF 10 KM. THIS COULD BE DONE IN ONE GO, OR OVER SEVERAL DAYS.

www.mouthcancerfoundation.org

Mouth Cancer FOUNDATION

Awareness and Support

Date/Time

FREE MOUTH CANCER SCREENING HERE FOR ALL TODAY!

Mouth Cancer FOUNDATION

Awareness and Support

MOUTH CANCER ACTION MONTH

Date/Time

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To make a donation or for FREE information visit www.mouthcancerfoundation.org

Advice Line: 01924 950 950 • Head Office +44 (0) 208 940 5680
Alternatively you can email info@mouthcancerfoundation.org



SCAN TO WATCH OUR 2 MINUTE SELF CHECK YOUTUBE VIDEO