



ISSUE 95 | NOVEMBER 2022 This month we are raising awareness about mouth cancer during Mouth Cancer Action Month. Our charity campaign is all about educating the public about risk factors, importance of checkups and prevention.

#### Editor's Welcome

Hello and welcome to a brand-new issue of Word of Mouth – the Oral Health Foundation's digital magazine. This edition is dedicated to our annual November campaign -- Mouth Cancer Action Month.

Throughout November, we have received an enormous amount of support from both health professionals and the general public, so I'm taking this opportunity to thank you for that!

Despite all the support and information provided, the new research shows that the cases have risen in the last year. That is why this issue of Word of Mouth begins with the article showcasing the effect the disease has on people.

Nevertheless, throughout this edition, we shine a light on the main risk factors, key warning signs, and other vital information about the disease. And to give you a glimpse into what it's like to live with mouth cancer, we present to you Robert and Charlotte -- mouth cancer survivors who have kindly agreed to share their experience with us.

Sounds interesting yet? If so, you will also be delighted to get a chance and discover the mystery of a mouth cancer research facility one of our colleagues has visited and agreed to showcase ber time inside

I won't take any more of your time now, we hope you enjoy this latest issue of the magazine!



**Viktoriia Davydenko**Editor, Word of Mouth







Be mouthaware and check for signs of mouth cancer

Mouth cancer: the 'big three' causes

Mouth cancer in young people: Charlotte's story

Healthy dad diagnosed with mouth cancer urges everyone to get check for signs and says "it can happen to anybody"

Mouth cancer: 6 major challenges

Wear a blue ribbon and start a life-saving conversation

Stepping inside a mouth cancer research facility

How we reduce the harm caused by mouth cancer



# Mouth cancers hit record high

New cases of mouth cancer in the United Kingdom have risen to a record high, according to the findings of a new report.

Figures collected by the Oral Health Foundation show that 8,864 people in the UK were diagnosed with the disease last year. This has increased by 34% compared to 10 years ago and has more than doubled (103%) within the last generation.

The findings are part of the charity's new <u>State of Mouth</u>

<u>Cancer UK Report 2022</u> and have been released to coincide with November's Mouth Cancer Action Month.

Dr Nigel Carter OBE, Chief Executive of the Oral Health Foundation, says the charity is fighting an uphill battle against mouth cancer and more must be done to raise awareness of the disease.

Dr Carter says: "While most cancers are on the decrease, cases of mouth cancer continue to rise at an alarming rate.

Traditional causes like smoking and drinking alcohol to excess are quickly being caught by emerging risk factors like the human papillomavirus (HPV).

The stigma around mouth cancer has changed dramatically. It's now a cancer that really can affect anybody.

"We have seen first-hand the devastating affect mouth cancer can have on a person's life. It changes how somebody speaks, it makes eating and drinking more difficult, and often changes a person's physical appearance.

"During Mouth Cancer Action Month, we will be raising greater awareness of mouth cancer. We urge everybody to become more 'mouthaware' by being able to recognise the early warning signs of mouth cancer and to be aware of the common causes. Most importantly, if you notice anything unusual, please don't delay and seek help from a doctor or dentist."

At 26 years old, Charlotte was given the life-changing news that she had mouth cancer.

The ex-cabin crew member, now training to be a midwife, does not fit the typical mouth cancer

patient – being a young woman who's a non-smoker and an active gymgoer. But Charlotte represents a growing number of younger people who are being diagnosed with mouth cancer.

Charlotte says: "I had some ulcers for about three to four years before I had my (mouth cancer) operation.

"I wasn't worried about them at first because I do get run down. I was jet-lagged and flying all the time with my job and often ulcers are sign of celiac disease, which I have, so I put it down to that. They came and went but always in the same area, they never fully went but they used to flare up like if I was run down.

"They felt like ulcers do, but just a bigger patch and they started to turn white, and they had like red around them as well, so they looked quite like inflamed.

"I thought maybe it was a bit of an infection or something. My mum kept telling me to go and get it checked so I went to my doctor who sent me for a biopsy.

"I went in for the results, and he asked, 'have you got anyone with you today?' I looked at him and said, 'it's not good is it?' He replied 'no, it's not. I'm really sorry, you've got cancer'. I remember saying to him 'what do you mean? Surely not,' and I think I almost laughed. It was such a shock because I'm otherwise a healthy person.

"There is a stereotype for mouth cancer. I was told 'oh, you're too young', 'God it won't be that'. But it really can happen to anyone."

Mouth cancer can appear as a mouth ulcer which does not heal, red or white patches in the mouth, or unusual lumps or swellings in the mouth, head or neck.

One-in-three mouth cancers (33%) are found on the tongue and almost one-in-four (23%) are discovered on the tonsil.

The other places to check for mouth cancer include the lips, gums, inside of the cheeks, as well as the floor and roof of the mouth.

Latest figures show that 3,034 people in the UK lost their life to mouth cancer last year.

This has risen by almost 20% in the last five years. Survival rates for mouth cancer have barely

improved in the last 20 years. One of the key reasons behind this is that far too many mouth cancers are diagnosed too late.

More than half (53%) of all mouth cancers diagnosed at stage IV - where the cancer is at its most advanced.

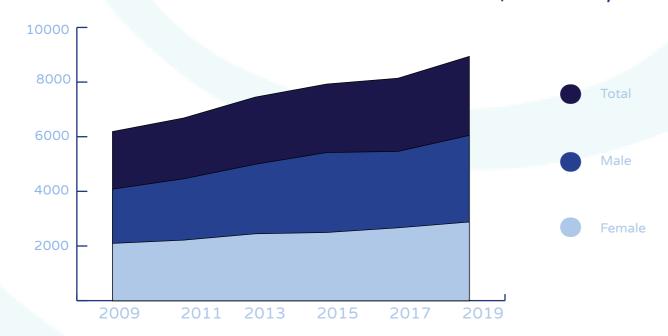
Dr Catherine Rutland, Clinical Director at Denplan, part of Simplyhealth, says getting into a routine of checking for signs of mouth cancer at home is crucial.

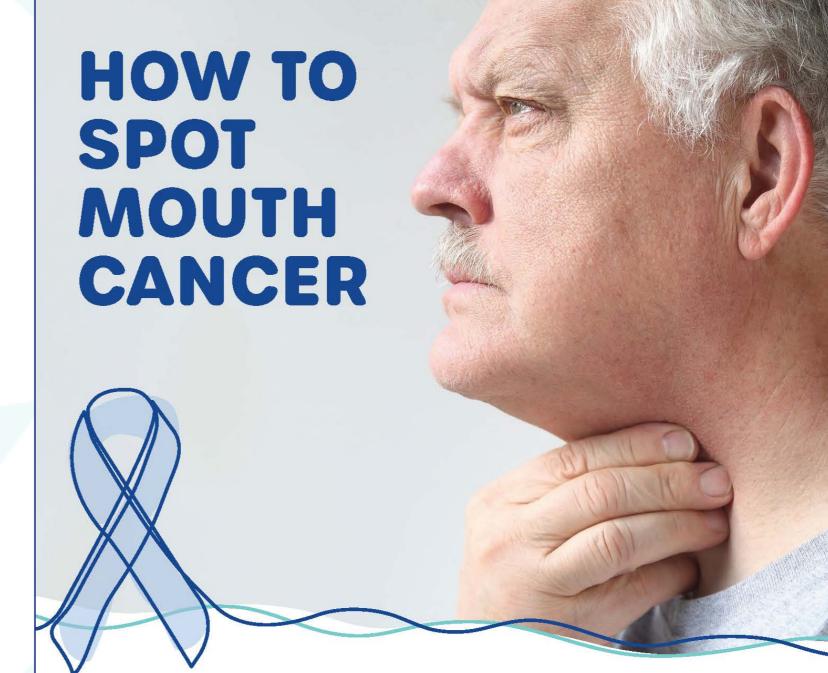
Dr Rutland says: "We know that mouth cancer doesn't discriminate against anyone, you can be making appropriate lifestyle choices and still be at risk and late diagnosis has a severe effect on a person's quality of life and their chances of survival. However, introducing simple checks as part of your oral hygiene routine will enable you to monitor any changes.

"A self-check for mouth cancer takes a minute and could save your life. If you notice anything out of the ordinary, visit your dentist, if mouth cancer is caught early, the chances to beat it are good."

More information about mouth cancer, visit www.mouthcancer.org.

#### Mouth cancer incidence in the UK | Year-on-year





#### WHERE TO CHECK FOR MOUTH CANCER

Look at your cheeks, gums, lips, tongue and tonsils.

Also check the roof and floor of your mouth, as well as your head and neck.

#### WHAT SHOULD YOU BE LOOKING FOR

Mouth ulcers that do not heal within 3 weeks.

Red or white patches in the mouth.

Unusual lumps or swellings in the mouth, head and neck.













# Be mouthaware and check for signs of mouth cancer

The number of people in the UK being diagnosed with mouth cancer has doubled within a generation but too few people know how to spot it early, according to the Oral Health Foundation.

New research by the charity as part of November's Mouth Cancer Action Month, shows that most people are unaware of what the early warning signs of the disease are and where it can appear.

Non-healing mouth ulcers, lumps, swellings, and red or white patches in the mouth are the most common signs, yet as little as half (51%) of UK adults would not be able to recognise them as symptoms of mouth cancer.

Poor awareness of the signs means more than half (53%) of all mouth cancers are diagnosed in stage IV – where the cancer is at its most advanced – leaving the chances of beating the disease up to as much as a coin toss.

Dr Nigel Carter OBE, Chief Executive of the Oral Health Foundation, says spotting mouth cancer early is essential for successful treatment and highlights the need for everyone to get into a routine of checking their mouth for signs of cancer at home.

Dr Carter says: "Spotting mouth cancer early can transform the chances of survival from 50% to 90%. Sadly, poor awareness of mouth cancer is often the reason why so many cases are caught too late.

"To reduce the number of lives lost to mouth cancer, it is essential that more people know how and where mouth cancer can appear. "It is really important for everybody to be mouthaware by being able to recognise and act on any unusual changes to the mouth. If you notice anything out of the ordinary, don't delay, visit a dentist or doctor straight away."

One-in-three mouth cancers appear on the tongue (33%) while almost one-in-four (23%) are found on the tonsil.

Mouth cancer can also occur on the lips, gums, inside of the cheeks, roof and floor of the mouth and the throat.

Figures collected by the Oral Health
Foundation show that 8,864 people in the UK
were diagnosed with the disease last year.
This has increased by 34% compared to 10
years ago and has more than doubled (103%)
within the last generation.

Karen, 49, was 'shocked beyond belief' to be told that a seemingly harmless mouth ulcer on her tongue was actually mouth cancer.

Before her diagnosis, the wife and mother-oftwo from Rochford, Essex, Karen described herself as a healthy person. She did not smoke or drink excessively, enjoyed running and eating healthy food.

Karen is determined to use her experience to help raise awareness of the disease and highlights the importance of knowing the early warning signs.

Karen says: "A lot of people think that mouth cancer only happens to smokers, but my story shows that isn't always the case.

"Always be alert to unusual change in your mouth and if you are worried, get it checked out. Don't be frightened. It's important that you don't suffer in silence and to remember that the sooner it's looked at, the sooner it can be sorted.

"Chances are it'll be fine but in the rare case it is not, it could be a life saver."

New research from the Oral Health Foundation and Denplan, part of Simplyhealth, shows that almost two-in-three (62%) have never checked their mouth for signs of cancer. UK adults are around three times more likely to conduct routine self-checks for testicular and breast cancer than for mouth cancer.

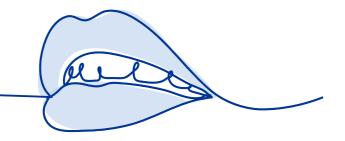
Further findings show more than four-in-five (83%) are either not confident about what they are looking for, or do not know what to look for at all.

Dr Catherine Rutland, Clinical Director at Denplan, part of Simplyhealth, adds: "A self-check for mouth cancer takes a minute and could save your life. By introducing simple checks as part of your oral hygiene routine, it will enable you to monitor any changes.

"If you notice anything out of the ordinary, visit your dentist, if mouth cancer is caught early, the chances to beat it are good."

1 minute check...

...can save your life.



## Mouth cancer -'big three' causes

By knowing the causes of mouth cancer, we can take positive steps to reduce our own level of risk, says a leading health charity.

The Oral Health Foundation is raising awareness about the causes of mouth cancer, following new research that shows far too many people remain unaware of the main risk factors.

The number of people diagnosed with mouth cancer in the UK has doubled in the last 20 years, with tobacco, drinking alcohol to excess and the human papillomavirus, being the considered the most common causes.

However, new data shows that awareness into the three big risk factors is as low as 15%.

With more than half of all mouth cancer cases linked to lifestyle factors, the charity along with Denplan, part of Simplyhealth, are using November's Mouth Cancer Action Month to shed light on the biggest risks factors associated with the disease.

#### Tobacco

Smoking tobacco increases your risk of developing mouth cancer by up to ten times. This includes smoking cigarettes, pipes or cigars.

As much as two-in-three mouth cancers are linked to smoking.

Dr Nigel Carter, Chief Executive of the Oral Health Foundation says: "Despite the number of smokers continuing to fall, it remains the leading cause of

mouth cancer. Our focus must be on providing smokers with the support and information they need in order to kick tobacco for good. It's never too late to quit and by making this positive step, the health of your mouth and body will see both instant and long-term benefits.

"It is important that government makes their smokefree target by 2030 a reality. To do this, more funding must be placed into smoking cessation services and campaigns which help more smokers to quit."

Smokeless tobacco, which is often popular with South Asian communities, is also a major risk factor of mouth cancer and can increase a person's risk by around seven times.

#### Alcohol

Drinking alcohol increases your risk of mouth cancer.

Research shows those who drink between 10 and 42 units of alcohol a week could be increasing their chances of developing the disease by as much as 81%. Cases of mouth cancer are nearly three times higher in people who drink regularly.

Data also suggests people who smoke tobacco and drink alcohol, triple their mouth cancer risk.

Dr Nigel Carter adds: "Clinical Director at Simplyhealth and Denplan, Dr Catherine Rutland, adds: "Just like tobacco, alcohol is a carcinogen and one of the main causes of mouth cancer. The soft tissue inside the mouth is highly vulnerable to the toxins of alcohol, where damaged cells can lead

"Cutting down on alcohol, both the amount you have and how often you have it, can significantly cut your risk of mouth cancer. The NHS Drink Free Days App is an example of a great tool that can help you reduce alcohol intake."

UK guidelines recommend a maximum of 14 units of alcohol a week for both men and women. This is around six pints of beers or seven glasses of wine.

#### **HPV**

The human papilloma virus (HPV) is a type of virus that infects the skin and the cells lining the moist areas of the body. HPV spreads through close skin-to-skin contact, usually during sexual activity. This makes the virus very common.

"For the majority of people, HPV is symptomless and causes no harm," says Dr Carter.

"Around 90% of HPV infections usually go away by themselves within two years, however, for some people they can lead to changes to the mouth and lead to cancer in the future.

"Practicing safe sex and limiting the number of partners you have may help reduce your chances of contracting HPV."

In the UK, girls and boys are offered the HPV vaccine at school in Year 8.

The charity believes the vaccine will go on to save millions from getting cancer.



### Only 11% are

aware that...

...HPV can cause

#### mouth cancer.

Karen Liesching-Schroder from Essex was 'shocked beyond belief' to be told that a seemingly harmless mouth ulcer on her tongue was actually mouth cancer.

Recently speaking on the Oral Health Foundation's podcast, Karen says: "I didn't suspect anything. I have never smoked, I didn't drink much, I was a runner, I was really quite healthy.

"A lot of people think that mouth cancer only happens to smokers, but my story shows that isn't always the case. I urge everyone to check their mouth once a month so that you are familiar with

what it looks like and feels like.

"If you are worried about an unusual change in your mouth then get it checked out. Don't be frightened but it's important that you don't suffer in silence and to remember that the sooner it's checked out, the sooner it can be sorted.

"Chances are it'll be fine but in the rare case it is not. it could be a life saver."

You can find more information on mouth cancer by going to www.mouthcancer.org and by following the campaign on social media via #MouthCancerAction.



#### TIME TO CHECK Be Mouthaware

A simple check for mouth cancer takes less than 1 minute and can save your life. Look for any signs in the mouth, tongue, lips, head and neck. If you spot anything out of the ordinary, visit your dentist.

The signs of mouth cancer

- Mouth ulcers that last more than 3 weeks.
- Red or white patches in the mouth.
- Unusual lumps or swellings.

www.mouthcancer.org











# Mouth cancer in young people: Charlotte's story





As part of November's Mouth Cancer Action Month, Charlotte Webster tells us her experience of mouth cancer. Charlotte hopes her story will raise awareness of the disease and encourage more people to check themselves for signs of mouth cancer.

At 26 years old, Charlotte was given the life-changing news that she had mouth cancer. The ex-cabin crew member now training to be a midwife from Hampshire does not fit the typical mouth cancer patient – being a young woman who's a non-smoker and an active gym-goer. But Charlotte represents a growing

# Every penny goes towards helping people achieve a healthy smile

Everybody deserves to have good oral health.

By donating to the Oral Health Foundation you are helping the most vulnerable people to achieve a healthier life through better oral health.

Every penny counts. Please donate today.

www.dentalhealth.org/donate



number of younger people who are being diagnosed with mouth cancer and also is just one of thousands of people who have been diagnosed with mouth cancer and had to face their treatments with the added struggle of COVID regulations and isolation.

Charlotte talks about her own journey, opens up about what led her to getting checked out, the disbelief of a diagnosis, and reveals how mouth cancer continues to change her life.

"I had some ulcers for about three to four years before I had my [mouth cancer] operation, but I wasn't worried about them at first because I do get run down and I was jet-lagged and flying all the time with my job and often ulcers are sign of celiac disease, which I have, so I put it down to that. They came and went but always in the same area, they never fully went but they used to flare up like if I was run down.

"About a year before I had my operation I went to the dentist and they said 'well, I don't really know what it is, might be because your teeth are rubbing so we would advise maybe getting your teeth straightened and have your wisdom teeth taken out. So, I did that. I paid for braces, got my wisdom tooth taken out and had really great teeth, but still had the ulcers."

After these initial early signs of mouth cancer were missed by her dentist and other professionals, Charlotte went on to have a biopsy in April 2021 after her ulcers got significantly worse.

"They felt like ulcers do, but just a bigger patch and they started to turn white, and they had like red around them as well, so they looked quite like inflamed. I thought maybe it was a bit of an infection or something. My mum kept telling me to go and get it checked so I went to my doctor in January and he said he wanted to send me for a biopsy which I got around April.

"I went in for the results, and he said, 'have you got anyone with you today?' And I was thinking yeah my other half is in the car with the dog. And he said, 'Do you want to bring him in?' and I just looked him and I said 'it's not good is it?' and he was like 'no, it's not. I'm really sorry, you've got cancer' and I was like, 'What do you mean? Surely not.' and I think I almost laughed. It was such a shock because I'm otherwise a healthy person."

Charlotte also told us about her time in intensive care.

"It was hard, and I remember I couldn't see mum which was really hard too. I couldn't wait to get out of hospital, as amazing as the staff were, my goal was 'right, just get home'. To get discharged you need to show the staff you can drink, swallow, keep stuff down, you know, all the rest of it. So, they listen to your swallow for a while and then they'll test it.

"My tracheostomy was fitted for seven days so my body hadn't swallowed or breathed through my mouth in so long that often your muscles take a while to get back to that. And I had to have my tracheostomy taken out, and I remember the first time they tried to take it out. They covered this hole so I could then breathe through here and it wouldn't, it just couldn't, I think my body wasn't ready because it was like being suffocated because I couldn't breathe through my mouth. it was so like, it's just like I had a mouth full of like straw or hay. It was just so hard, so husky, so stuck. And I remember the panic, I was like no, I can't, so they tried again the next day and then every day it just got a bit better and better."

After getting home from the hospital, Charlotte continued to get support from different professionals including counsellors, dieticians, and speech therapists, but also emphasised how important she found the support she got on social media from other mouth cancer sufferers.

"It's a different kind of like support that you get because you know that they feel the same, like one guy said to me 'I saw your video of you sipping the water for the first time. I laughed my head off because I felt exactly the same!' and before my operation there was one lady who said she would chat to me, but I chose to speak to her after my op because I just wanted to, not really know much, I just wanted to get it done and out the way. But afterwards I messaged her about one of the things I was most worried about — I asked her to send me a voice note because I wanted to know that I wasn't going to sound like you couldn't understand me that was the only thing I was worried about. Because I know unfortunately it does happen to some people, but she reassured me."

Charlotte also shared some thoughts about mouth cancer in young people.

"There is a stigma against mouth cancer, I was told 'oh, you're too young', 'God it won't be that', 'no it won't be that', and it does happen. It really can happen to anyone not just smokers because that's such a stigma - it really annoys me. People think you have to be like a really old man that smokes 50 a day, but you don't. It took this tiny little poster in the clinic for me to, to be like, 'oh my God, that's mouth cancer' and by then it was too late anyway."

Learn more about mouth cancer by visiting www.mouthcancer.org.



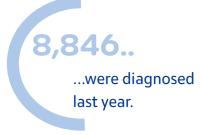


## THE STATE OF MOUTH CANCER

Most of us have heard of cancer affecting parts of the body such as the lungs or breasts. However, cancer can appear in our mouth, where the disease can be diagnosed in areas like the lips, tongue, cheeks and throat.

Be mouthaware by knowing more about mouth cancer. It could save your life.

THE NUMBER OF PEOPLE BEING DIAGNOSED WITH MOUTH CANCER, AND LOSING THEIR LIFE TO THE DISEASE, IS INCREASING...



34%... ...more than 10 years ago.





Two in three are men.



Four in five are over 55.

#### WHAT CAUSES MOUTH CANCER...

91%

of mouth cancers are linked to lifestyle.



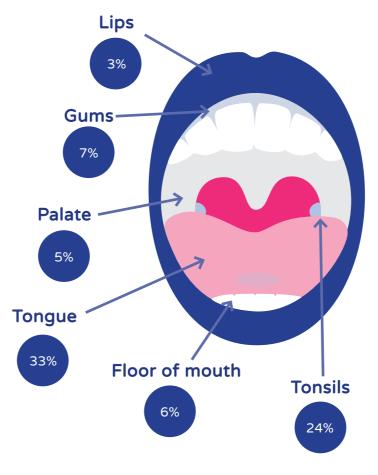






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#### WHERE MOUTH CANCER APPEARS...



...BUT AWARENESS OF THE DISEASE REMAINS WORRINGLY LOW...



17%
Recognise the signs.



9%
Understand the causes.

### LIVING WITH MOUTH CANCER IMPACTS A PERSON'S PHYSICAL AND MENTAL WELLBEING....

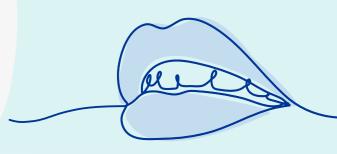
**→** BREATHING

**EATING** 

**DRINKING** 

→ SPEAKING

**DEPRESSION** 





83%

Not confident doing a self check.

By knowing where mouth cancer appears and what causes it, you give give yourself the very best chance of spotting it early, and even lowering your risk.

You you notice anything out of the ordinary, visit your dentist or doctor immediately. If in doubt, get checked out.





# Healthy dad diagnosed with mouth cancer urges everyone to get check for early warning signs and says "it can happen to anybody"

#### "It'll go away. It can't be that serious".

That's what father of four, Robert Powell, told himself when he came down with a persistent sore throat.

It happened shortly after the London-born business consultant, along with his wife Susie, moved to France to open up a bed and breakfast.

Robert suffered with tonsilitis as a young child, so a sore throat was nothing out of the ordinary.

"In those days, they used to whip your tonsils out at the drop of a hat but despite having several bouts of tonsillitis, they left them in," Robert says. "I just thought, I've got a sore throat and it'll go away. I did the blokey thing and ignored it."

It took Robert several months before accepting that he needed help. Coming back to the UK routinely for work, Robert visited a GP who prescribed him some antibiotics. When the medication did not ease the pain in the back of Robert's mouth, he decided to seek the advice of a dentist.

Robert adds: "One day, I was doing training at a dental practice and said, 'would you mind taking a look at this?'. The dentist put me in the chair, took one look before bringing in a colleague. They immediately said, 'when you return to France, you need to see somebody urgently'.

"I went back later that week. Like the UK, the French health care system is very good. They were rapid. I made a call and went in for a consultation. The next day I was in a specialist unit for a biopsy and two days later I received the diagnosis that I had mouth cancer on my tonsils.

"This was my 62nd birthday. Quite the present."

A human biology and immunology graduate from the University of London, Robert has spent much of his adult life working in healthcare.

Because of his work alongside dental practices, Robert was aware of mouth cancer, but it wasn't that high up on his agenda. He did not smoke or drink an excessive amount of alcohol. Robert considered himself a fit and healthy person.

"When I was told that I had mouth cancer, I was in disbelief," Robert says. "A feeling of denial that it can't possibly happen to me. I lived healthily and didn't think I was in a risk factor group. For a time, I detached myself from it all and convinced myself that it's fine and nothing to worry about.

"The news effected the children more. We had the family over for the holidays and they were thinking is this going to be the last Christmas? It was that thought which made me think it was really serious."

Thankfully, Robert's cancer was caught early. He underwent a 12-week course of chemotherapy and radiotherapy and has since been able to make a good recovery.

However, the lasting impact of mouth cancer continues to be with him.



# Your mouth matters. The Oral Health Foundation is here for you.

We care about your oral health.

That's why, every year, we support thousands of people to help them achieve a healthier life through better oral health.

If you need help, or would simply like to support us in our mission, visit our website and get in touch.

www.dentalhealth.org



Robert adds: "I still suffer with a dry mouth, as the radiotherapy damaged my salivary glands.

"I also struggle a lot with taste... which for somebody who enjoys their food, living in France on wine and cheese for four years, that's a big problem. If I eat a bar of Cadbury's I can tell what it is for the first 30 seconds, but after that, it may as well be margarine. I also used to enjoy a vindaloo but now a korma seems hot."

Due to Robert's treatment, he also needs to wear a mouthguard filled with fluoride gel when he sleeps. He will need to do this for the next five years, to help strengthen his teeth and maintain good oral health – something that many mouth cancer survivors face difficulties with.

Robert has become a mouth cancer ambassador for the Oral Health Foundation, to share his experiences and raise awareness of the disease that has changed his life.

Spotting mouth cancer early is crucial for beating the disease and Robert urges everyone to be more aware of the changes that occur inside their mouth.

Robert says: "The lesson I took away is that even if you are a non-smoker, you are still at risk.

You can't sit there and be complacent and think this can't happen to me. So many people like myself, will make the mistake of dismissing the symptoms and think they will go away.

"Mouth cancer can happen to anybody, however fit or normal you think you are. That's why regular dental check-ups are so important. Having a specialist like a dentist look in your mouth routinely is as vital as cervical screening or a breast cancer check. Even if there's nothing there, it's the reassurance. Regular dental check-ups can be a matter of life or death."

Mouth cancer can appear on the tonsils, tongue, gum, cheek, head and neck.

Be alert to mouth ulcers which do not heal within three weeks, red and white patches and unusual lumps or swellings. Persistent hoarseness, or a numbness on the lips or tongue are the other common signs. If you notice any of these symptoms, visits a dentist or doctor immediately.

You can find more information on mouth cancer by going to <a href="www.mouthcancer.org">www.mouthcancer.org</a> and by following November's Mouth Cancer Action Month on social media via #MouthCancerAction.

Visit your dentist or doctor immediately if you spot...

Numbness of the lips/ tongue.

> Long-lasting red/ white patches.

Lumps or swellings, persistent hoarseness.

# Mouth cancer: 6 major challenges

Mouth cancer cases continue to rise, with the disease effecting more lives every year.

Reducing the devastation caused by mouth cancer is one of the Oral Health Foundation's most important and urgent tasks. Within this fight, there are a number of problems to address, ranging from awareness and dental access, to economics and government policies.

Here are some of the most significant challenges that are linked to mouth cancer:

#### The rising cost of living

In 2022, inflation in the UK reached a high of 10.1%. With people struggling to heat their homes or feed their families, many are being forced into unfair and unjust choices. Findings by the Oral Health Foundation show that as many as one-in-five (23%) UK adults have avoided making an appointment at the dentist because of the rise in cost of living.

This includes basic check-ups, treatments, as well as the expenses involved in travelling to the dentist. To bring in more household income, one-in-ten (11%)

are now working more hours and are unable to find the time to attend the dentist.

Rising costs are an increasing barrier to dental attendance – a critical avenue for early mouth cancer diagnosis, a better quality of life and surviving mouth cancer.

#### **Dental access**

A growing population, coupled with a dwindling NHS dental workforce is leading to a crisis in dental access.

In England alone, the number of NHS patients seen in the last 24 months has declined by 26% compared to before the pandemic. Those who find it more difficult to access dentistry often include the elderly, people with mobility difficulties, individuals in geographically isolated areas and those from minority ethnic backgrounds.



Mouth cancer is strongly related to age and there are also a growing number of cases in South Asian communities. Dental access is essential for timely referrals and early diagnosis for mouth cancer. Because of this, it is essential that more people are able to access NHS dentistry.

#### Late diagnosis

Late diagnosis of mouth cancer is all too common and has a severe effect on a person's quality of life and their chances of survival. Nearly two-in-three (63%) patients are diagnosed in stages III and IV.

#### <u>Chances of survival based on</u> <u>late diagnosis</u>



Overall, just under half (53%) are diagnosed in stage IV, when the cancer is at its most advanced. Public awareness of the signs and symptoms remains exceptionally poor. Also, given the nature of mouth cancer, even health professionals have difficulty spotting the disease before visual symptoms present themselves.

#### The protection of public health policies

A large proportion of mouth cancers are linked to causes and could be prevented with a change in lifestyle choices. The two of the most common and destructive risk factors linked to mouth cancer are tobacco and drinking alcohol.

When combined, these two cause triple a person's mouth cancer risk. For many people, tobacco use, and excessive alcohol intake is not a choice, it is an addiction. As a result, the government has a duty of

care to protect the population from harm.

In recent months there have been worrying noises coming out of government regarding important public health policies such as Smokefree 2030 pledge. Diluting or removing such policies would be a disaster for mouth cancer rates.

#### **HPV** vaccinations

In the UK, schoolboys and schoolgirls are eligible for the HPV vaccination. The vaccine is the most effective route for protecting people against HPV cancers and diseases, including mouth cancer.

WHO have set a global coverage target of 90% for one dose, however, a newly published report shows the UK falls well short of that. School closures and child absences following COVID-19 has meant that coverage in some regions of the UK is as low as 67% (East of England).

The two-dose vaccination uptake has also decreased from 84% before the pandemic, to 57%. It means that 317,581 children in year 9 went without a second HPV vaccine dose last year while 147,337 have gone completely unprotected.

#### Tax on cancer

In addition to the overwhelming emotional and psychological impact that mouth cancer can have, survivors can also be challenged with several oral health issues.

Chronic toothache, tooth loss and dry mouth are just some of the common problems that require long term dental care. Frequent dental treatment is often a necessity for mouth cancer victims.

With NHS dental charges ranging from £23.80 to £282.80 in England, the recurring costs over the course of a year can soon mount up. We estimate that mouth cancer sufferers can expect to pay up to £1,500.00 over five years for dental treatment, significantly higher than average.

www.yumpu.com/en/document/read/67107065/eating-with-confidence

#### EATING WITH CONFIDENCE

RECIPES FROM AN ORAL CANCER SURVIVOR



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WRITTEN BY

LAURA 'DIZZ' MARSTON

# Wear a blue ribbon and start a life-saving conversation

The Oral Health Foundation is persuading everyone to take part for the Blue Ribbon Appeal to spark potentially life-saving conversations about mouth cancer.

For Mouth Cancer Action Month, the oral health charity is promoting the powerful effect of wearing an enamel blue ribbon badge. A small gesture that they believe can help put a halt to rising numbers of mouth cancer cases in the UK.

Dr Nigel Carter, Chief Executive of the Oral Health Foundation, spoke about the role the Blue Ribbon Appeal plays in the campaign and why you should pick one up.

Dr Carter says: "Cases of mouth cancer have risen sharply over recent years. It's a topic that many of us would rather not discuss but the bottom line is, we need to talk about it.

"We must raise awareness of this disease, especially to those who are at a high-risk of developing it. This is where the Blue Ribbon Appeal can make a difference.

"Wearing a blue ribbon badge can help bring a difficult topic out of the dark and into the light.

It can spark conversations about mouth cancer and encourage the people around you to be mouthaware by keeping an eye on what's going on inside their mouth.

"Being proactive is vital, so use the Blue Ribbon Appeal as a way of getting ahead. Let's talk about this major issue before it becomes a problem for ourselves or someone we hold dear."

This year, the Oral Health Foundation is hoping to build on the 250,000 Blue Ribbon Appeal badges that have been received by supporters over recent years. The funds generated by the appeal are in aid of Mouth Cancer Action Month and helping spread key information about the disease as far as possible.

"Not only does the badge serve the purpose of spreading vital information, it also acts as a sign of solidarity," Dr Carter adds.

"A person is diagnosed with mouth cancer approximately once every hour.

"We want to show that we stand together arm-in-



arm with the countless people who have been in some way affected by the disease.

"Wearing a blue ribbon badge is an easy way to get involved and help raise awareness.

"Mouth Cancer Action Month really isn't the same without your support. Please get involved as much as you can and thank you to everyone who is planning to help spread awareness in November and beyond."

The Blue Ribbon Appeal Kit is available to purchase

from £1 per badge, from the <u>Oral Health Foundation</u> <u>online shop</u>.

Simply leave the collection box on your reception desk for patients to donate. We also encourage all staff members to wear a badge during the campaign – as it is a great way to show support as a team and to strike conversation with patients too!

Once collected, please donate to us the money you have raised by visiting the <u>Oral Health Foundation's</u> website.



# Stepping inside a mouth cancer research facility

Inside the Blizzard Institute in London, Dr Adrian Biddle took us behind the scenes inside a mouth cancer research facility and talked to us about his work and how it is going to improve the lives of so many cancer patients.

The research Dr Biddle is conducting aims to find out which parts of a tumour are driving it to spread, and if we're able to isolate this, we can determine how likely it is someone's cancer is going to spread, and from that make better-informed decisions about treatments. He does this thanks to the donation of cancer tissue from patients, which is then grown under controlled conditions in his lab so he can monitor it closely and document changes.

He told us "One which we are particularly interested in is whether we can better target neck dissection. So at the moment, a lot of patients get a neck dissection where alongside their surgery to remove their lymph nodes, because this is where the tumour spreads to

and we know it gives better clinical outcomes.

So, it's an important surgery for people to have if they need it. But we know that there's no good way of talking about surgery now and deciding which patients need it. So what I'd like to do is improve on that.

"What we've done is taken a laboratory model we're using where a cancer cell spread within a 3D matrix and asking 'Can we develop a signature of those cancer cells which is spreading and apply that in patients to see if we can then identify which patient's tumours are going to spread? Did they have a mild case or were they more unfortunate?'

"So we took this laboratory model, developed a



signature for these cells, which is spreading, and then we applied that initially to preserve patient specimens. The archive of patient specimens we have will have linked with the clinical data from the patient and their treatment, which shows how the patient's tumour developed.

"And what we found is that in this initial small study, we present a patient specimens. I see that she was very good at predicting whether a tumour is going to spread or not. We were really excited by this so now we're looking and applying for funding to make this into a bigger study. And if that works well and continues to give it really good predictive accuracy, then this is something which we we're really excited to apply clinically so that when patients come for their initial biopsy, they could have got tested for this signature."

This could save hundreds - if not thousands - of people from undergoing unnecessary treatments."

He does acknowledge, however, that these things take a long time and have a long process to go through before they can be brought out to the public.

"The clinical development is, unfortunately, often quite slow. And it often seems that research isn't

making a difference, but actually, if you look at the research, that was happening ten years ago, that's already now helping patients.

"Equally, there are increasing efforts now to identify ways to screen patients for early-stage lesions and early-stage changes in their oral cavity, which may indicate that they're going to possibly progress to cancer, which means that these tumours can be identified much, much earlier. So that's a huge area of research which I think is starting now to have some clinical impact."

All of Dr Biddle and his team at the Blizzard Institute's research is contributing to making the chances of detecting, treating and beating mouth cancer higher than they are currently, as he also adds "I think it's important that as we progress all kinds of research, we're always thinking about most important clinical problems currently so we can make sure that we are tackling what's happening".

If you're diagnosed with mouth cancer, and are wondering how you can help mouth cancer research, speak to your medical team to see if you can participate in any clinical trials or are able to be a participant in a suitable study.



#### **BE MOUTHAWARE**

& CHECK FOR CHANGES IN THE MOUTH

# **HEAD & NECK** CHEEK MOUTH

LIPS

#### TONGUE

Mouth cancer can affect anybody and it's important that we all know what to look out for. If you notice any changes in your mouth please speak to a dentist or doctor immediately.

NECK













## How we reduce the harm caused by mouth cancer

The challenges to reduce the growing number of people affected by mouth cancer are complex - and the solutions can be even more difficult.

Over the last 20 years, the Oral Health Foundation has invested over £2m in mouth cancer awareness. Our commitment doesn't change – we want less people to have mouth cancer, and less people to lose their life from the disease. These are our ambitions, but we must make them a reality.

Here is our top list of key recommendations for reducing the harm caused by mouth cancer.

#### Improving education and awareness

Despite the number of mouth cancer cases continuing to increase, mouth cancer awareness remains extremely low. Awareness around the causes of mouth cancer is as low as 9% while around half have no knowledge around the early

Time is key when it comes to mouth cancer, if you believe you or someone close to you has any symptom, get it checked out by your dentist or doctor straight away.

**Dr Nigel Carter,** Chief Executive of the Oral Health Foundation

warning signs.

Mouth cancer receives little or no national attention when it comes to cancer awareness programmes. Future campaigns focusing on the risk factors and how to spot mouth cancer should receive greater support from policymakers, media outlets, celebrities and influencers.

This year, the Oral Health Foundation has become a founding member of two new coalitions - the Head & Neck Cancer UK Coalition and the HPV Coalition. With the support and backing of more like-minded organisations and charities, these coalitions have the ability to transform how much the public knows about mouth cancer.

#### **Boosting HPV vaccine uptake**

Coverage of HPV vaccinations in schools must increase in-line with, and even beyond that of, before the pandemic. With significant regional and local variations in uptake, there must be a priority towards increasing vaccination in populations with low coverage.

To help increase vaccination uptake, all parents of Year 8 and Year 9 children should receive information about HPV and the HPV vaccination, including when and how their child's vaccinations will take place.

This information must also be made available to children and young people who do not attend schools (e.g., home schooling). Invitations and reminders about the HPV vaccination must be sent out routinely. This could involve other health and social care providers that are in contact with the family to help gain consent where contact cannot be made through the school. Incentives for returning consent forms has also been proven to be successful for increasing vaccine uptake.

#### Free dental check-ups for mouth cancer patients

The current NHS dental contract arrangements do not allow all patients recovering from mouth cancer to receive free restorative treatment on the NHS.

Many of these patients will have complex and expensive restorative needs for life. This issue is made even worse by the fact that generally patients must pay for the privilege of asking their dentist for a potentially life-saving examination to detect the cancer in the first place. In our opinion, there would be a public outcry if patients with any other type of cancer were asked to contribute to the cost of their reconstructive treatment and lifelong care.

It is an issue that needs to be put right to ensure that mouth cancer sufferers do not have the

financial burden for returning their lives to normal and recovering from their condition, which often involves major facial surgery.

Free dental checks for mouth cancer patients after their treatment has strong support. Nearly fourin-five (78%) of the general public and nine-in-ten (90%) dental professionals support the proposals.

#### <u>Training for health</u> <u>professionals and carers</u>

Many people are now seeing doctors and pharmacists about problems with their mouth. This includes symptoms of mouth cancer.

Mouth cancer is recommended Continuing
Professional Development (CPD) for dental
professionals but very little is taught about
the disease in wider healthcare. Mouth cancer
information and education should be routinely given
to non-dental health professionals.

Care home, nursing staff and other carers must also be trained to look for signs of mouth cancer, in addition providing effective oral hygiene and oral health care and support.

#### Investing in NHS dentistry

NHS dentistry continues to perform a remarkable service, despite being continually underfunded by successive governments. The current dental contract needs a major overhaul. Reforms to

remove the current UDA payment system and replace with a capitation based contract would go a long way in restoring NHS dentistry and making it fit for purpose.

There also needs to be a committed plan from government to address the workforce issue – the UK simply needs to train more dentists.

In the Autumn, Rishi Sunak vowed to restore NHS dentistry if he was made Prime Minister. He now must honour this pledge by increasing funding, encouraging dentists to stay part of the health service and having a much stronger focus on prevention.

#### Reinforcing health policies

Legislation is the most effective route for reducing incidence and mortality of mouth cancer. There are a number of smoking and alcohol policies that could be adopted.

The Oral Health Foundation supports an outright ban on smoking and urges the new Secretary of State for the Department of Health and Social Care, Steve Barclay, to prioritise public health by reinforcing tobacco control policies and alcohol legislation.

Smokefree 2030 must not be softened or abandoned while health warnings on alcohol packaging and minimum unit alcohol pricing should also be brought in. We also recommend extending the powers of pharmacists, so they are able to issue referrals for mouth cancer.

To achieve our goals and transform the landscape of mouth cancer in the UK, we need your support. We cannot do this alone.

If you would like to help us campaign on any of the above issues, please join us as a mouth cancer ambassador at <a href="https://www.mouthcancer.org">www.mouthcancer.org</a>.

### MOUTH CANCER RISK FACTORS



There are a number of risk factors that increase your chance of developing mouth cancer.

By understanding your own risk, you can make positive changes to reduce the likelihood of being diagnosed with mouth cancer.

It is important to remember that if any or most of these apply to you, it doesn't mean that you will develop mouth cancer. Be alert by conducting self checks at home and regularly visiting the dentist.



Smoking tobacco increase your risk by up to ten times. This includes cigarettes, pipes or cigars.



Drinking alcohol to excess is linked to a third of all mouth cancers. Guidelines recommend a maximum of 14 units a week.



The human papillomavirus (HPV), spread through oral sex, is now one of the main causes.



Chewing and smokeless tobacco, such as gutka, betel quid, zarda, snuff and nass.



A third of mouth cancers are linked to an unhealthy diet and a lack of vitamins and minerals.



Too much ultraviolet (UV) radiation is a known cause of skin cancer and can develop on the lips.



Those who have had a mouth cancer are at greater risk of developing it again.



Those who have had oesophagus cancer (of the food pipe), skin, cervical, penile and anal cancer.



There is a slight increase if you have a close relative diagnosed with the disease.



Links have been found for those with genetic conditions affecting the bone marrow, skin or fingernails.



Those undergoing treatment for HIV or AIDS and those taking medication after organ transplants.













## **WORDOFMOUTH**

#### Magazine

We want to know what sort of content you want to see!

Would you like to know more about gum disease? How about a Q&A with one of our dental experts to answer some of your burning questions? Or perhaps you want to hear more about our fantastic range of educational resources?

Let us know by emailing pr@dentalhealth.org

