

Oral Cancer Care
Local Guide

prevention - early-detection - referral - care

Advice and guidance for the primary dental care team



Supported by
Cancer Research UK Facilitators



Dympna Edwards



Mohsan Ahmad

One in two people in the UK will get cancer at some stage in their lives and oral cancer rates have increased by over a third in the last 10 years. Preventative intervention, early detection and appropriate referral can save lives.

Oral cancer incidence rates in the UK are projected to rise by another third between 2014 and 2035. The latest figures show that more than 8,300 people in the UK are diagnosed with oral cancer each year. 1 in 75 men and 1 in 150 women will be diagnosed with oral cancer during their lifetime. General dental practitioners and their teams are ideally placed to aid in the early detection of oral cancer. By examining clinically and assessing risk factors appropriate urgent '2 week' referrals can be made via the GM electronic referral management system; that will allow practices to track the progress of the referral.

To support Dental Teams in Greater Manchester, the GM Local Dental Network has adapted the Oral Cancer guide created by Cheshire and Merseyside LDN. We engaged with patients, local dental practitioners, Cancer Research UK and the Managed Clinical Networks for Oral surgery and Restorative Dentistry.

We believe that this guide will complement the previous Primary Care Dental toolkits that have been created by the GM LDN. Reinforcing our aim to support GM Dental teams to provide quality dental services with excellent patient outcomes and experience.



Dympna Edwards,
Consultant in Dental Public Health



Mohsan Ahmad,
Chair Local Dental Network. (Greater Manchester)



Dental teams are at the frontline in providing oral care for our communities. With an increasing incidence of oral cavity cancers, dental teams play a crucial role in the prevention and early detection of oral cancers.

They are also central to the management of dental conditions in those treated previously with chemotherapy or radiotherapy for head and neck cancer. I commend the authors of this dental toolkit for oral cancer care, which clearly describes recommendations along the patient pathway to decrease the incidence of oral cancer, improve oral cancer survival rates and reduce late treatment effects. This toolkit will support our dental teams to provide the very best care, improve patient experiences and outcomes for oral cavity cancer.

Dr David Thompson

Greater Manchester Pathway Director for Head and Neck Cancer



The tickling in my ear was the red flag that the lesion on my tongue was more serious than it appeared.

Patients seen for routine dental checks may not see their own GP for years so dentists and hygienists play a vital role in the early detection and referral of head and neck cancer. Being confident to advise patients on reducing the risk of oral cancer, having the discussion when you suspect something and knowing how to refer quickly is really important to your patients.

Having had radiotherapy, very invasive dental treatment, such as extractions and more risky root canal work need referring to a dental hospital as the healing ability of the jaw has been compromised. This shared care keeps me well."

Nic Clews

Patient representative, GM Cancer



I am currently living with the effects of throat cancer. And with all head and neck cancers the impact on your mouth and teeth can be easily forgotten but is in fact very important.

Prior to treatment I had a full dental check up and any necessary dental work done. This made my teeth and gums as healthy as possible during treatment. After treatment my mouth was more sensitive and prone to infection so care from the dental team is crucial in keeping your mouth in good condition. Dentists can give sound advice on dental care, for example the use of fluoride toothpastes and mouthwashes.

This guide provides sound practical advice for the dental team in the care of their patients. I wholeheartedly recommend it. Providing regular check-ups, advice and a listening ear are the most important things you can do for patients after treatment for head and neck cancer.

Richard Delleman

Patient representative, GM Head and Neck Pathway Board

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01 | Introduction to the Oral Cancer Guide



SECTION 1 - INTRODUCTION

Summary

- Cancer affects more and more of our patients.
- 1 in 2 people will get cancer at some stage in their lives.
- Survival has doubled since 1970s so more patients have had cancer.
- Oral cancer has increased by 40% in last 10 years.
- Dental teams have an important role in prevention, early detection and dental care of people with cancer and oral cancer.

"My dentist reacted quickly to my tongue cancer and sent me for a biopsy. The team have shown sympathy and care throughout my cancer journey."

JM - Oral Cancer patient

Dental teams will treat many patients who have had cancer. Cancer is very common and one in two people born after 1960 in the UK will develop cancer at some stage in their lives. Cancer isn't a single disease. There are more than 200 different types of cancer. Dental teams have an important role in cancer prevention and in understanding and managing the impact of cancer treatment on oral health and dental care.

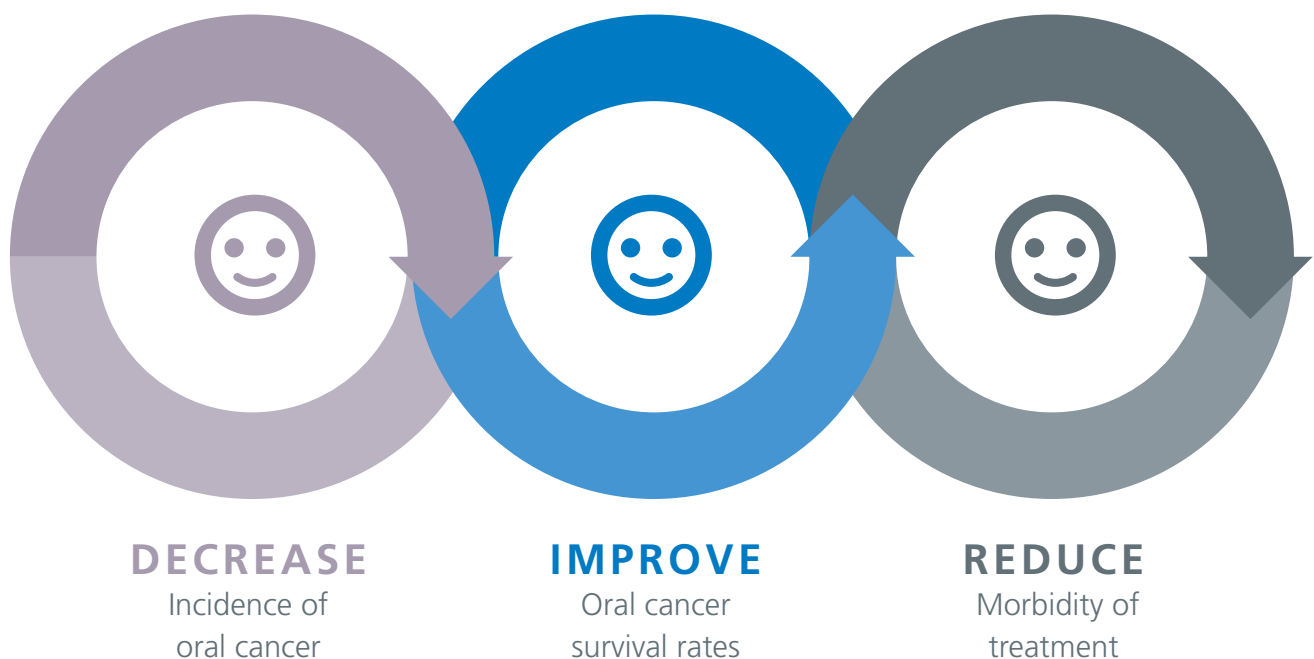
The prevention, early identification and ongoing care of patients with cancer and oral cancer is vital. It is a key contribution that the dental team can make to the health and wellbeing of our patients and the community as a whole. Patients tell us that they need and want integrated care and dental teams have an important role in the care of people with at risk of oral cancer or who have had oral cancer.

Dental teams have a particular role in screening for oral cancer, early detection and referral of patients with a suspicious lesion through a 2-week referral. How dental teams communicate with patients can help them to understand and manage risk factors. Patients can be reassured and supported during the investigation process.

There is a considerable amount of information and guidance available which can help the dental team in the management of patients who have presented with a suspicious lesion, enabling appropriate referral to a secondary care cancer service, together with the provision of timely preventative interventions for those patients whom may be at risk. These include:

- NICE guideline (NG12).
- British Dental Association / Cancer Research UK National Oral Cancer Toolkit.
- Public Health England: Delivering Better Oral Health Toolkit for Prevention.
- Public Health England: Smoke Free and Smiling – Helping Dental Patients to Quit Tobacco.
- Health Education England: Making Every Contact Count.
- Greater Manchester Healthy Living Dentistry Programme
- Referral management system- oral cancer section
- Commissioning better oral health for vulnerable older people

This guide includes key recommendations from these documents, offering easily accessible local information and tools to help.



1.1. Aim of the local guide

To improve the oral cancer survival rates in Greater Manchester by:

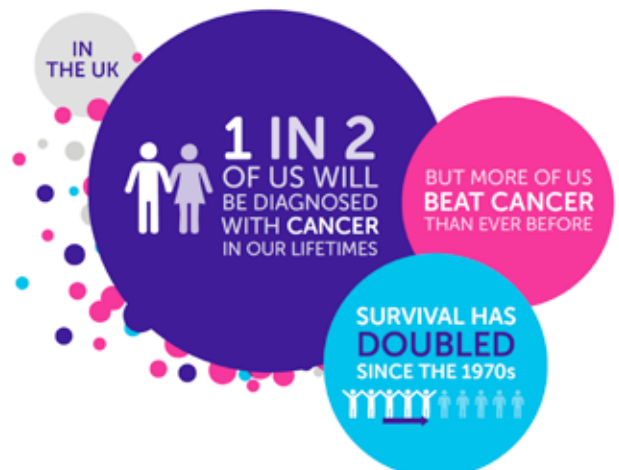
- Enabling dental teams to support patients in reducing risk factors for cancer and oral cancer and undertake brief intervention, including signposting to support services as part of a healthy living dentistry approach to care.
- Raising awareness of the signs, symptoms and risk factors associated with oral cancer.
- Helping dental teams in GM to make appropriate urgent 'Two Week' referral to a secondary care cancer service.
- Promoting good practice guidance on how to engage when talking about oral cancer with high risk patients.
- Supporting dental practices in the dental care of patients with oral cancer and other cancers.

1.2. Cancers

Every one of us knows someone who has had cancer. Cancer isn't a single disease. It can occur in different sites in the body and at different ages and there are more than 200 types of cancer. What they all have in common is that they involve cells that have been damaged and grow more quickly than the normal cells. This growth can be slow or rapid and cause minimal problems or be life threatening.

Although cancer can occur at any age it is most common in older age groups. As people are living longer more people are getting cancer. Life expectancy has increased from 71 to 81 years since the 1960s.

The good news is that survival has doubled since the 1970s, a dramatic improvement. This means that dental practices will see more people who have or have had cancer than they would have done a few decades ago. Much of this improvement is due to earlier detection through screening programmes and better treatment.



Source: Cancer Research UK

1.3. Oral Cancers- National picture

The term head and neck cancer includes over thirty different subsites ranging from the lip and oral cavity to the lymph nodes in the neck. Oral cancer or mouth cancer refers to cancers in the mouth or oropharynx.

In the UK:

- 1 in 75 men and 1 in 150 women will be diagnosed with oral cancer during their lifetime. It is twice as common in men as in women.
- Just over half (51%) will be in people aged 65 years or older.
- There were around 8,100 new cases of oral cancer in 2015¹.
- There were 2700 deaths from oral cancer in the UK in 2016.
- Oral cancers make up 3% of all cancers in the UK.
- In the last 10 years oral cancer incidence has increased in the UK- from 9 cases per 100,000 people between 2003-05 to 13 per 100,000 in 2013-15. The increase is larger in women than in men.
- Incidence rates of oral cancer are projected to rise by a third in the UK between 2014 and 2035.
- Head and neck cancer in England is more common in people living in the most deprived areas.
- Risk factors for oral cancer are related to tobacco, alcohol consumption and diets low in fruit and vegetables.
- Recent findings indicate a sharp rise in the incidence rates of oral pharynx cancer linked to human papillomavirus, particularly effecting the younger adult population.

1.4. Greater Manchester Incidence and Prevalence

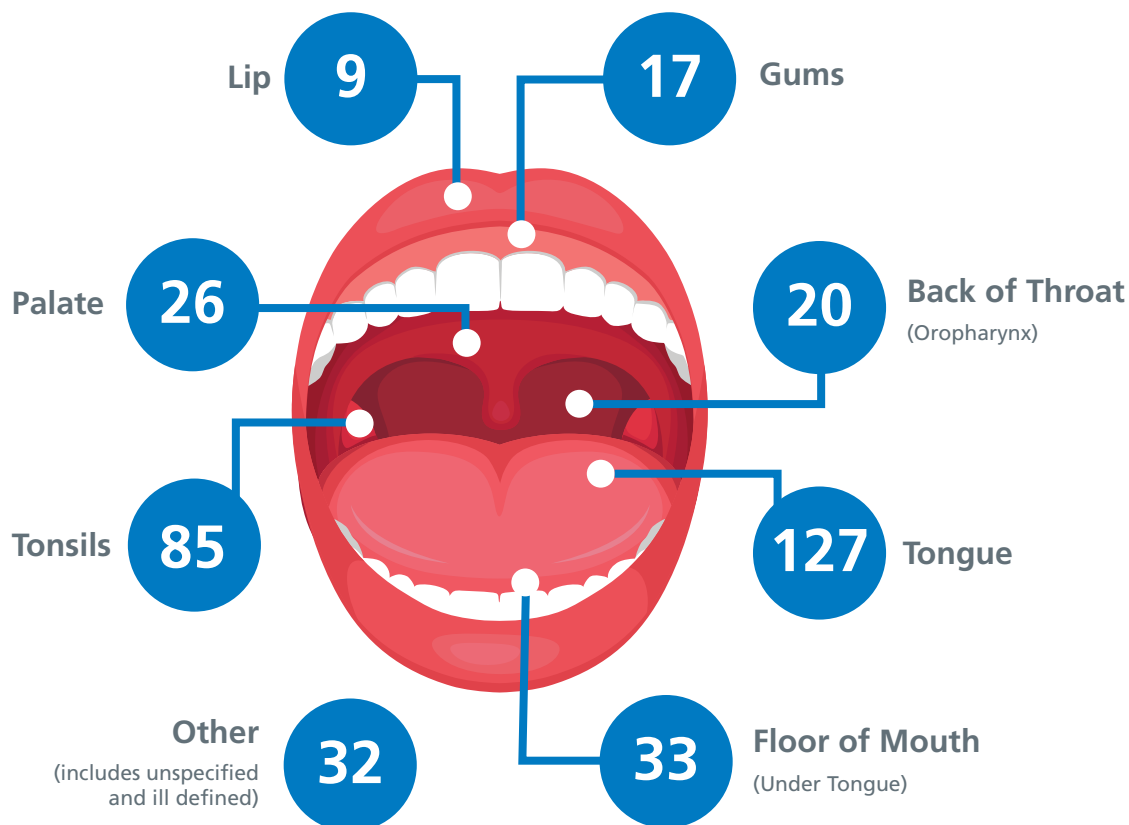
Between 2013-2015 1882 people in Greater Manchester were diagnosed with oral cancer and 331 people died from oral cancer.

Oral cancer prevalence is higher in Greater Manchester than for England as a whole and particularly high in Manchester and also higher than the national average in Rochdale, Tameside, Bolton, Bury and Salford.

¹ CRUK figures based on new cases diagnosed in 2015 (ICD10 C00-06, C09-10, C12-14).

1.5 What counts as Mouth Cancer

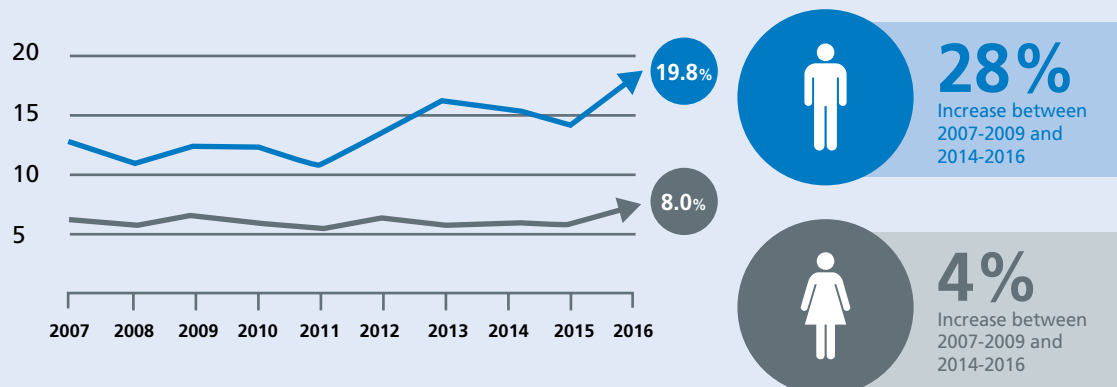
Sites of mouth cancer and the average number of cases per year GM, 2014-2016



Source: National Cancer Registration & Analysis Service (NCRAS), Public Health England

Mouth Cancer Rate

Incidence rate of mouth cancer per 100,00 population, GM



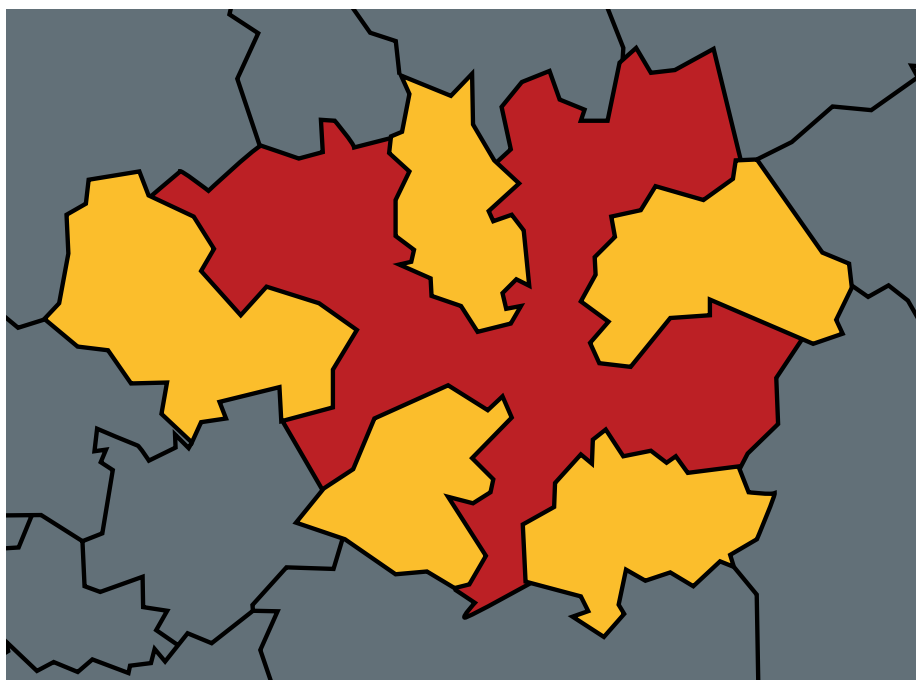
Source: National Cancer Registration & Analysis Service (NCRAS), Public Health England

Oral Cancer Registrations (2014-16)

Area ▲▼	Count ▲▼	Value ▲▼
England	22,006	14.7
CA-Greater Manchester	1,245	17.9
Bolton	135	17.9
Bury	82	15.9
Manchester	222	24.8
Oldham	98	16.5
Rochdale	110	19.9
Salford	109	18.2
Stockport	128	15.0
Tameside	121	19.3
Trafford	94	15.3
Wigan	146	15.8

Source: PHE - National Cancer Registration and Analysis Service retrieved from the Cancer Analysis System (CAS)

Map of oral cancer registrations by local authority compared to England Average 2014-16



Compared with Benchmark

Better

Similar

Worse



02 | Prevention



SECTION 2 - PREVENTION

Summary

- About half of oral cancer cases can be prevented
- Smoking, alcohol, HPV and diet are the main risk factors.
- Very brief advice can help people to reduce their risk of oral cancer and other cancers too.
- Most oral cancer patients said that their dentist hadn't given them any advice on preventing oral cancers and would have liked to have this.

"No one told me about the risks of head and neck cancer. All dentists should have information leaflets to inform patients about head and neck cancer."

JMcM - Cancer patient

This section has been designed to support dental teams to understand the risk factors for oral cancer, to undertake brief interventions and signpost patients to services that will help them to reduce these risks.

2.1 Prevention in dental practice.

The major risk factors for oral cancer are tobacco use, HPV infection, a diet low in fruit and vegetables and alcohol use. Dental teams are in a good position to identify health risks and to provide advice, signposting and support for patients. Many dental professionals have done this for years and it is an established part of routine care and recommended practice for all NHS professionals.

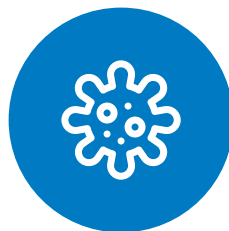
Almost Half of all UK mouth* cancer cases could be prevented



**Drink less
alcohol**



Be smoke free



**Protect against
certain infections**



Eat healthily

* oral cavity

Source: Brown et al, British Journal of Cancer, 2018

2.2 Drivers of prevention



**"This is part of
Healthy Living
Dentistry in GM-
providing holistic care
for our patients and
showing we care"**

Dympna Edwards
Greater Manchester Health and
Social Care Partnership 2019.



'Every Contact Counts.'
**Brief intervention,
referral and or
signpost.**

Smoke free & smiling helping dental
patients to quit tobacco.
Public Health England 2017.



**Delivering Better
Oral Health.**
**An evidence based
toolkit for prevention.**

Department of Health/
Public Health England 2017.

2.3 Brief intervention

The dental profession has the potential to save lives by providing planned or opportunistic advice to large numbers of “healthy” people. We have an ethical duty of care.

A brief Intervention is a tool to empower people to take responsibility for their own health & wellbeing.

A brief intervention can be:

- Planned but could also be opportunistic
- Structured simple information
- A motivational technique
- Involves follow up
- The provision of other support
- Signpost and or referral



Recognising when someone is thinking about changing:

- Weighing up pros and cons
- Expressing they want to change



How can we encourage?

- Don't tell them what to do!
- Show empathy and understanding
- Increase self-belief by showing support and focusing on strengths

Also raise the issue and find out if they want a chat:

Examples of conversation starters:

- "How are you feeling today....how's your health?"
- "Would you like some support around your diet/drinking/increasing physical activity? Is this something I can help you with?"
- "You said you smoke, have you thought about stopping?"

2.4 Healthy Living Dentistry Scheme

The Greater Manchester Healthy Living Dentistry Scheme developed by the Local Dental Network is a quality framework for dental practice that provides training and support for dental teams to improve the health of their patients.

Each Practice has a health champion who is offered A Royal Society of Public Health Level 2 training qualification. The practice undertakes 6 health campaigns per year to raise the awareness of risks to oral health and support their patients in making changes that they want to make. To hear what local dental teams say and find out more visit www.cpgmhealthcare.co.uk/dental.html

Support for patients on lifestyle changes is available through your local authority or the GM health hub.

2.5 The skills needed for Brief Intervention:

Rapport building

Being non-confrontational and approachable will help, introductions, positive body language, creating conducive environment.

Reflective listening

Reflecting and summarising on what's been said, repeating key words, checking and clarifying allowing for silences, eye contact.

Empathy

Building trust and understanding helps to obtain useful information.

Support

Recognise attempts to change behaviour, appreciate efforts and show belief they can change, increases confidence.

Sensitivity

Understand the individuals' life context.

The dental team have a role to play whether planned or opportunistic.



**All it takes is
30 seconds to
save a life.**

2.6 Brief advice on smoking

Smoke and smokeless tobacco is the leading cause of preventable death. Tobacco use in England continues to kill more than 70,000 people every year, nearly 1,900 of these people die from oral cancer.

It is vital that members of the dental team engage users of tobacco, offering brief intervention and advice regarding smoking cessation services.



Very Brief Advice on Smoking *30 seconds to save a life*



ASK

And record smoking status.
Is the patient a smoker, ex-smoker or non-smoker?



ADVISE

The best way of quitting smoking is with a combination of medication and specialist support.



ACT

On patients response!
Build confidence, give information, refer, and prescribe.
They are up to four times more likely to quit successfully with support.

**REFER THEM TO THEIR LOCAL
STOP SMOKING SERVICE**

For further information please go to: www.nhs.uk/smokefree

2.7 Brief advice on alcohol consumption

Alcohol misuse is a significant public health problem in England. Drinking above the lower risk guidelines significantly increases the risk of oral cancer.

Unit Guide

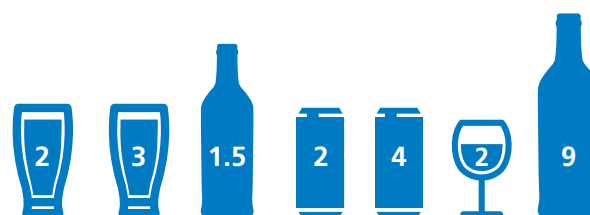
1 unit is typically:

Half-pint of regular beer, lager or cider;
1 small glass of low ABV wine(9%);
1 single measure of spirits (25ml)



The following drinks have more than one unit

A pint of regular beer, lager or cider, a pint of strong/premium beer, lager or cider, 440ml regular can cider/lager, 440ml "super" lager, 250ml glass of wine (12%)



Men and women are advised not to regularly drink more than 14 units a week. Many people underestimate how much they drink. The most reliable way of assessing people's alcohol intake is to incorporate the Audit C 3 screening questions below into your medical history form.

AUDIT - C Questions	Scoring System					Your score
	0	1	2	3	4	
How often do you have a drink containing alcohol?	Never	Monthly or less	2-4 times per week	2-3 times per week	4+ times per week	
How many units of alcohol do you drink on a typical day when you are drinking?	1-2	3-4	5-6	7-8	10+	
How often have you had 6 or more units if female, or more if male, on a single occasion in the last year?	Never	Less than monthly	Monthly	Weekly	Daily or almost daily	
Total						

Add up the total scores. A score of more than 5 would trigger some additional questions in the AUDIT tool below that explore the impact of the person's alcohol intake. The results of the two are added together to form an overall risk score.

This can be accessed online at

www.gmmh.nhs.uk/download.cfm?ver=1017

Supporting people to make Small Changes – Big Benefits:

- Make a plan
- Have a drink free day every week
- Keep track of how much you drink
- Limit the total amount of alcohol you drink on any single occasion
- Drink more slowly, drinking with food, and alternating with with water

Swap your usual drink for a:

- Smaller one
- Lower strength one
- Sugar free soft drink
- One mealtime only drink

Benefits of reducing Alcohol intake:

- A lower risk of developing many forms of cancer including oral cancer
- A lower risk of brain damage
- A lower risk of high blood pressure
- A lower risk of liver disease
- Having fewer hangovers
- Improved memory
- Sleeping better
- Feeling happier and less anxious
- Losing weight
- Having more energy

AUDIT - Questions After completing 3 AUDIT-C question on previous page)	Scoring System					Your score
	0	1	2	3	4	
How often during the last year have you found that you were not able to stop drinking once you have started?	Never	Less than monthly	Monthly	Weekly	Daily or almost daily	
How often during the last year have you failed to do what was normally expected from you because of drinking?	Never	Less than monthly	Monthly	Weekly	Daily or almost daily	
How often during the last year have you needed an alcoholic drink in the morning to get yourself going after a heavy drinking session?	Never	Less than monthly	Monthly	Weekly	Daily or almost daily	
How often during the last year have you had a feeling of guilt or remorse after drinking?	Never	Less than monthly	Monthly	Weekly	Daily or almost daily	
How often during the last year have you been unable to remember what happened the night before because you have been drinking?	Never	Less than monthly	Monthly	Weekly	Daily or almost daily	
Have you or somebody else been injured as a result of your dinking?	No		Yes, but not in the last year		Yes, during the last year	
Has a relative or friend, doctor or health worker been concerned about your drinking or suggested you cut down?	No		Yes, but not in the last year		Yes, during the last year	
Total						

Low audit score 0-7
Low consumption

Well done but remember to keep a check.

Audit score 8-15
Medium consumption

You may be drinking at a level that could put your health at risk. A few small changes could make all the difference.

Audit score 16+
High consumption

It may be worth speaking to your GP, a loved one or get specialist advice.

2.8 Human Papilloma Virus (HPV)

The HPV family of viruses are implicated in a number of cancers including cervical cancer and oral cancer and is largely responsible for the increase in oral cancers over the past 10 years in younger age groups.

A vaccination programme in girls aged 12-13 years in school has resulted in a 90% reduction in cases of cervical cancer. This programme is now being extended to boys aged 12-13 years in schools and will offer some protection against oral cancer. Newer vaccines cover more of the HPV strains of virus. Dentists can encourage parents to have their children vaccinated.

2.9. Fruit and Vegetables

Dental teams are familiar with providing dietary advice for patients in relation to dental caries and can encourage healthy eating. Being overweight increases the risk of 13 cancers. A diet that is high in fruits, vegetables, wholegrain foods and pulses and low in sugary drinks, processed and red meat reduces the risk of many cancers. Although the media often reports stories about certain foods that are supposed to increase or decrease the risk of cancer it is unlikely that specific "superfoods" on their own affect cancer risk. More information is available on www.cancerresearchuk.org/about-cancer/causes-of-cancer/diet-and-cancer.

2.10 Sun Safety

Over exposure to ultraviolet (UV) light from the sun or sunbeds increases the risk of skin and lip cancer. It is more common in people who have worked outdoors. The dental team are in a good position to provide advice on sun safety and to notice changes in the skin and lips.

2.11 Approaching the discussion

Many people are not aware that they have a problem or may be worried that they will be criticised or judged. Be sensitive and listen.

This is about helping people not making judgements or telling people what to do.

4 IN 10 CANCER CASES IN ENGLAND CAN BE PREVENTED...



●●● Larger circles indicate more England cancer cases

Circle size here is not relative to other infographics based on Brown et al 2018.

Source: Brown et al, British Journal of Cancer, 2018

Further information and support

The following website www.gmhealthhub.org has information on services for tobacco, alcohol, and healthy eating. You can signpost patients to these services.

Cancer resources

www.cancerresearchuk.org

Health and wellbeing for adults

www.nhs.uk <https://www.nhs.uk/oneyou/>

Health and wellbeing for families

www.nhs.uk/change4life

Smoking

www.nhs.uk/smokefree

Alcohol & other substances

www.nhs.uk/live-well/alcohol-support/NHS

www.drinkaware.co.uk

Diet and eating well

www.oneyou.gov.uk

Sugar smart

www.nhs.uk/change4life



03 | Early detection, referral & patient support



SECTION 3 -

EARLY DETECTION, REFERRAL & PATIENT SUPPORT

Summary

- Check the mouth to rule out oral cancer at each exam and tell your patients that you have done a check.
- If there are any suspicious lesions refer using the GM urgent electronic referral system as an urgent 2 week referral.
- Take photos if possible.
- Fewer than 1 in 10 of referrals are confirmed as cancer.
- Tell patients that you have referred them to rule out oral cancer.
- Follow up the referral to ensure the patient is seen within 2 weeks.

"It was my dentist that sent me to the consultant. This was after the doctor dismissed it as nothing serious. Unfortunately, the original referral in June went missing but he referred me again urgently in the September."

SM - Oral Cancer patient

This section has been designed as a reference tool to assist with; early detection, making an urgent 'Two Week' referral and patient support.

3.1 Local good practice guide - urgent 'Two Week' referral

3.1.1 Scope:

This good practice guide has been developed to support the dental team when making an urgent 'Two Week' referral to a secondary care cancer service for a suspected cancerous mass or lesion. It is designed to offer referral guidance and help to ensure a good patient experience.

The tools below are available in an electronic format at www.dental-referrals.org

For definition: Urgent:

- Referral made within 12 hours of patient presenting
- Patient to be seen by specialist within 2 weeks

If you are unsure about making an urgent referral it is good practice to seek the opinion of another dentist at the time of presentation. **If there is any doubt an urgent referral should be made.** In all cases the patient must be fully informed. Recent findings indicate that only 8% of urgent 'Two Week' referrals are cancerous, this is very reassuring.

This section contains the following tools:

1. Referral flow chart and log, which can be used to track and record the referral process (**Figure 1**).
2. Good practice referral proforma (**Figure 2**)
3. Patient information leaflet that can be adapted and given to the patient following consultation (**Figure 3**).

Please note:

This is not a mandatory document. The application of this good practice guide does not supersede in any way the responsibility of the dentist to make decisions that are appropriately tailored to meet individual patient needs and preferences.

3.1.2 Responsibility:

It is the responsibility of the dentist to:

- Comply with verifiable continuing professional development in line with General Dental Council standards and recommendations.
- Conduct intra and extra oral hard and soft tissue examinations at every dental check-up, irrespective of age, gender, religion, ethnicity or social class.
- Remain vigilant during courses of treatment.
- Identify suspected cancerous masses and or lesions and make appropriate, timely referrals.
- Ensure that patient's address and telephone number including mobile number are correct.
- Maintain accurate and contemporaneous patient records. Digital photography is an excellent method of supporting your record keeping, but also sending along with a referral.
- Follow-up patient referral, attendance and outcome.
- Fully inform the patient why an urgent 'Two Week' referral is required.
- Discuss possible diagnosis both benign and malignant.
- Lead and manage any dental care professional who provides support in-line with their relevant scope of practice and level of competency.
- Ensure that the dental team are aware of this good practice guide.

It is the responsibility of the dental care professional to:

- Comply with verifiable continuing professional development in line with General Dental Council standards and recommendations.
- Remain vigilant and appropriately escalate any observations or patient comments or concerns immediately.
- Comply with good practice guidelines.

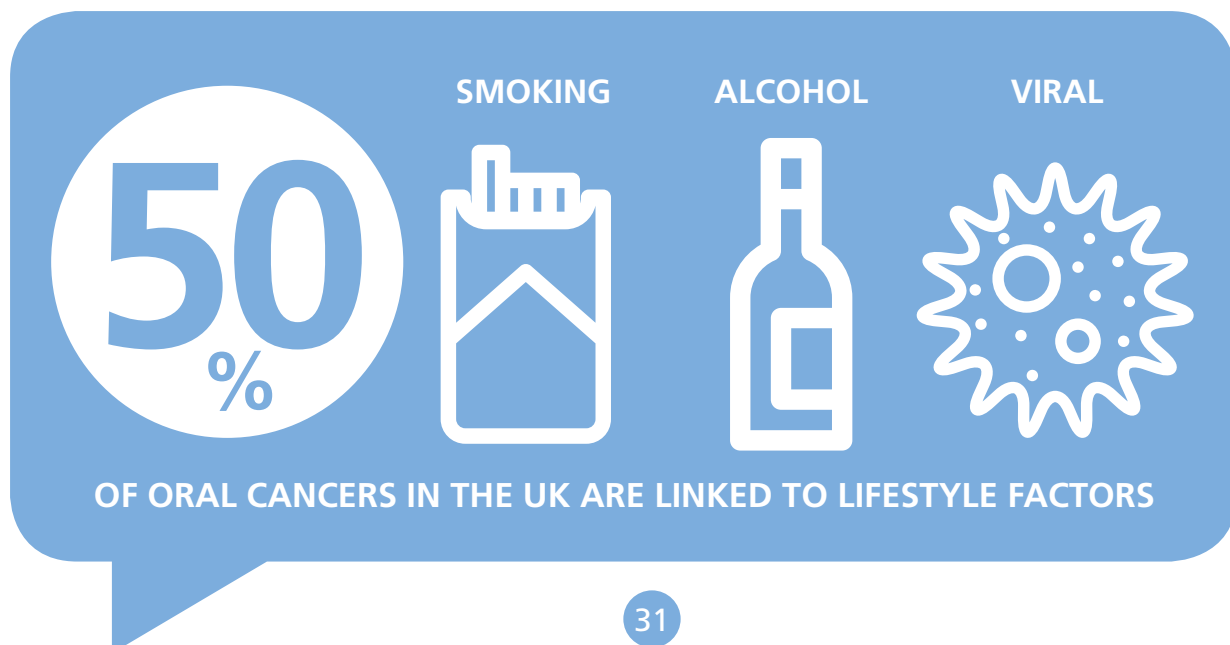
3.2 Oral cancer risk factors:

Cancer Research UK states:

An estimated 91% of oral cancers in the UK are linked to lifestyle factors.

A person's risk of developing oral cancer depends on many factors such as:

- Smoker
- Ex-smoker
- Alcohol consumption
- Paan / Betel Quid / Khat chewing
- Poor diet – low fruit and vegetable consumption
- Genetics
- HIV/AIDS
- Human papillomavirus
- Age
- Previous head and neck cancer
- Previous cancer treatment
- Previous radiation
- Immunosuppressed



3.3 Oral examination:

When doing an oral examination, it is good practice to adopt a systematic approach.

Systematic approach

- Lateral tongue
- Floor of mouth
- Gingivae
- Lips & vestibule
- Buccal
- Hard & soft palate
- Oropharynx
- Neck palpation

3.3.1 Signs and symptoms that trigger an urgent 'Two Week' referral:

The following is for guidance only and is by no means exhaustive. The dentist should ultimately exercise his/her own clinical judgement taking into consideration all relevant, authoritative and up to date professional guidance.

Extra-oral:

- Persistent unexplained head and neck lumps for more than three weeks.
- Persistent hoarseness lasting for more than three weeks.
- Ear pain without evidence of local abnormalities.
- Thyroid swelling in a pre-pubertal patient.
- Thyroid swelling with one or more of the following risk factors:
 - Neck irradiation.
 - Family history of endocrine tumour.
 - Unexplained hoarseness.
 - Cervical lymphadenopathy.
 - Patients age 65 and over.
- Cranial neuropathies.
- Orbital masses.
- Solitary nodule increasing in size.



Also be aware of possible changes due to skin cancer:

- Change in colour, size and shape of an existing mole.
- Moles with asymmetry, border irregularity, colour irregularity, diameter increasing or greater than 6mm.
- New growing nodule without pigment.
- Persistent surrounding inflammation or altered sensation for more than four weeks.
- Any unexplained skin lesion in an immuno-suppressed patient.
- Spot or sore that doesn't heal in four weeks.
- Itchy, crusty or bleeding skin nodule.
- Skin ulceration without cause.

Intra-oral:

- Ulceration or unexplained swelling of the lip or in the oral cavity for more than three weeks.
- All red/white or mixed red and white patches, of the oral mucosa that are painful or swollen or bleeding, consistent with erythroplakia or erythroleukoplakia, persisting for more than three weeks.
- Dysphagia or odynophagia (pain on swallowing) lasting for more than three weeks.
- Pain in the throat lasting for more than three weeks.
- Unexplained tooth mobility not associated with periodontal disease.

3.3.2 Record keeping:

When consulting with your patient it is important that you record clinical status, signs, symptoms, referral process and what information and advice you gave the patient both verbally and in writing. If digital photography is available then this will support the records.

Records should be kept In-line with authoritative and professional guidance.

To help you do this we have created a referral flow chart and log (Figure 1).

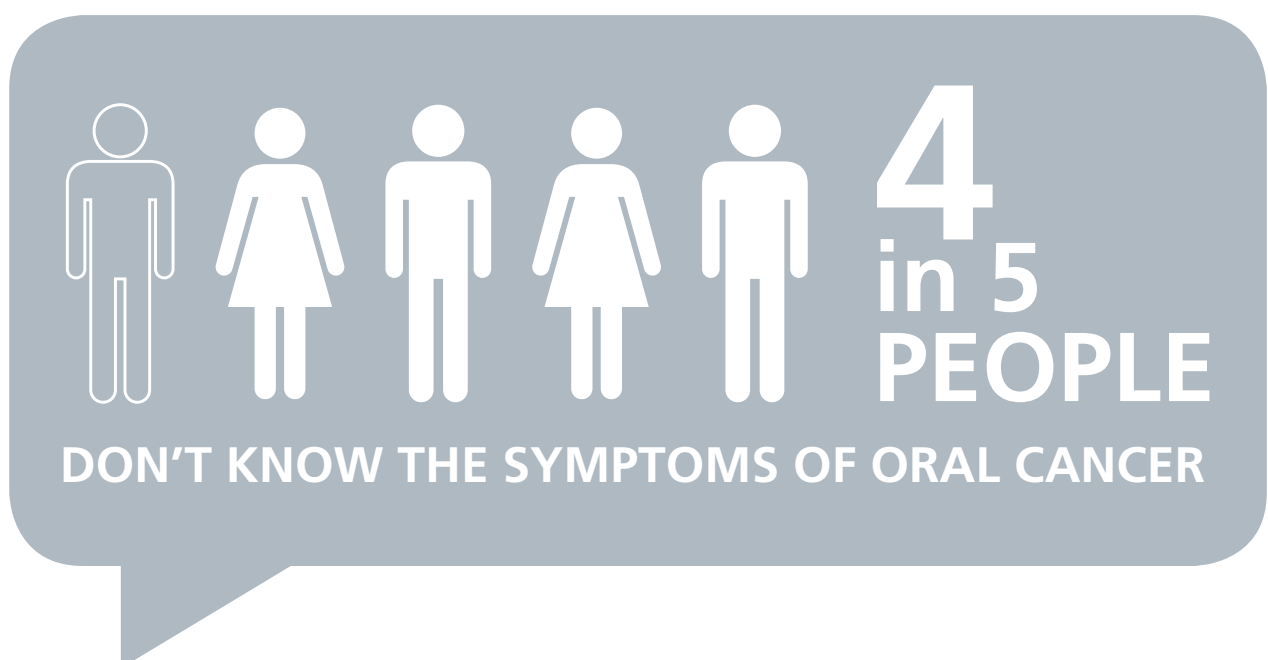
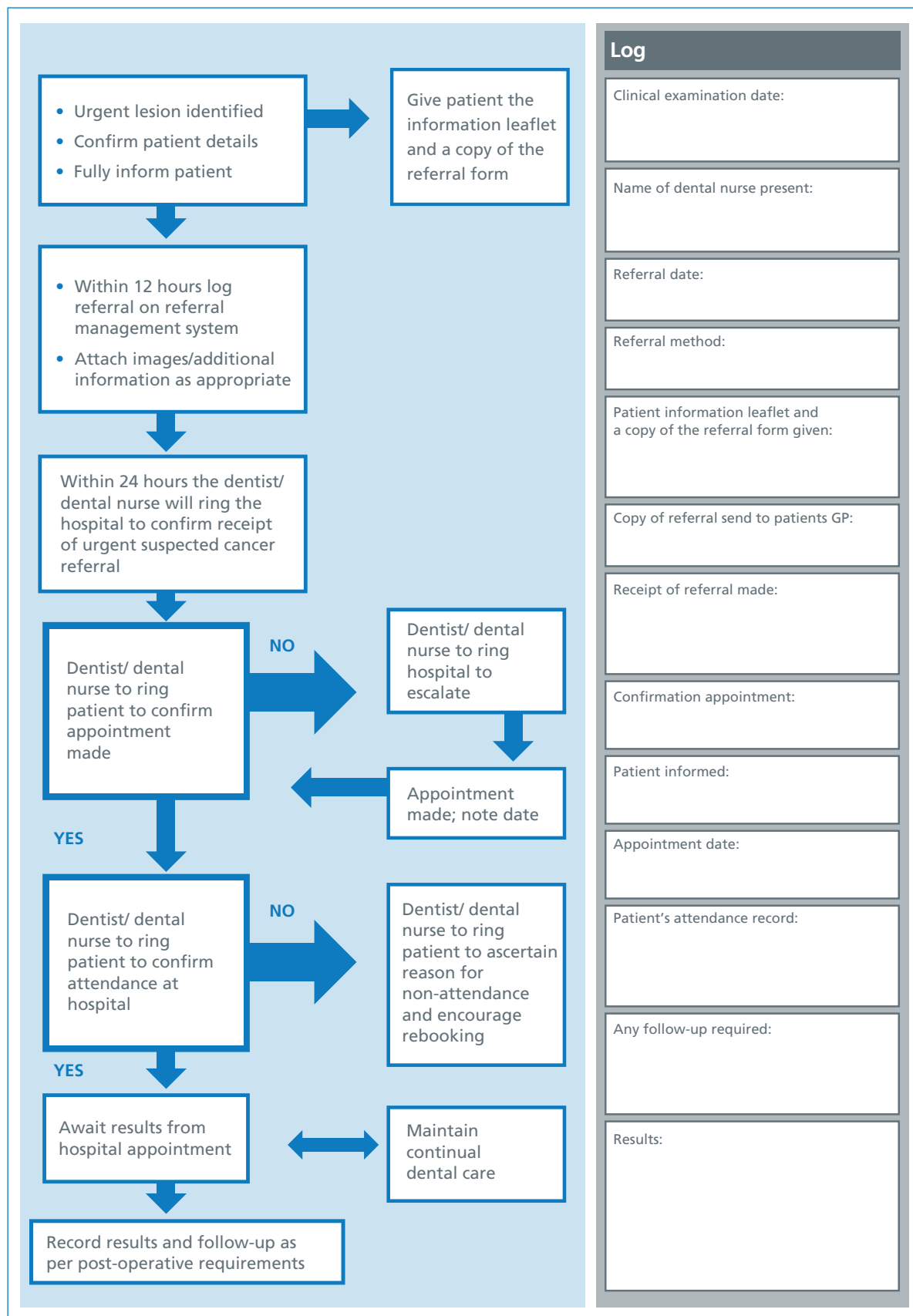


Figure 1. Good practice urgent referral flowchart and log:



3.4 Making a referral:

When making a referral it is vital that you provide relevant information to the secondary care cancer provider, to enable an efficient, informed medical appointment.

Referral Information required:

Patient: title, name, gender, date of birth, address, postcode, up to date phone number.

- Culture, mobility, disability, NHS eligibility and any impairment issues.
- Need for language translation or interpretation.
- Referrer name, practice address and postcode, phone number, General Dental Council registration number, date of decision to refer.
- Also include patient's general medical practitioner's name, practice address, post code and phone number.
- Medical history in-line with General Dental Council guidelines.
- X-rays or additional information as appropriate, eg. Photos.
- Reported risk factors.
- Current clinical presentation, including signs and symptoms.
- Confirmation that the patient is aware and fully informed regarding the need for an urgent 'Two Week' referral for a suspected cancerous mass or lesion.

To help you to make a good practice referral we have created a referral form template (Figure 2) and a directory of secondary care cancer providers.

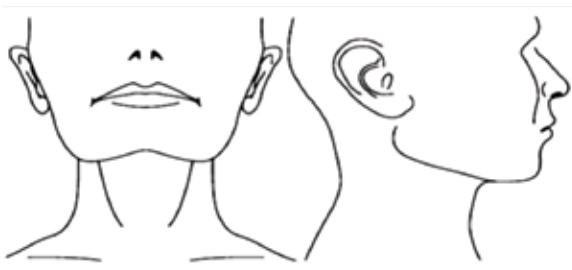
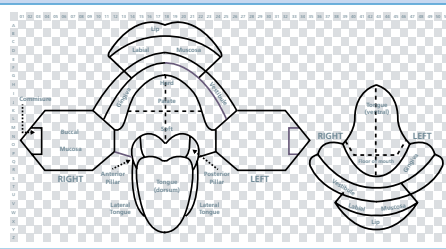
Please note:

If a Local general medical practitioners asks a dentist for an urgent opinion regarding a patient with a suspected lesion it is deemed good practice to see the patient on an urgent basis for a one off assessment appointment, even if the patient is not registered with the dental practice.

Figure 2. Referral form template:

Good practice referral form TEMPLATE.

SUSPICIOUS LESION URGENT TWO WEEK PATHWAY ONLY

Age of Patient in years:	Patient's Title & Name:	Gender:	Date of Birth (DD/MM/YY)
Patient's Address:		Preferred Contact Number:	Patient's Postcode:
Dentist Name:	Practice Postcode:	Date of Decision to Refer: / /	
Practice Name and Address:		GDC Number:	Practice Telephone Number:
Patients GMP Name and Address:		GMP Postcode:	GMP Telephone Number:
The patient is aware and fully informed regarding the need for the referral: ☐ YES ☐ NO		The patient has been given an information leaflet and a copy of this referral form: ☐ YES ☐ NO	
The GMP has been sent a copy of this referral form: ☐ YES ☐ NO			
Culture, Mobility, Impairment Issues: ☐ Is the patient from overseas? ☐ Is the patient a temporary visitor to the county? ☐ Is disabled access required? ☐ Is transport required?			Ethnic Origin: Religion:
Area of Suspicion: ☐ Oral cavity ☐ Pharynx ☐ Thyroid ☐ Larynx Neck / lymph node ☐ Ear ☐ Nose ☐ Other Please state...		Risk Factors: ☐ Poor diet ☐ Smoker ☐ How many per day? ☐ Ex-smoker ☐ For how long? ☐ Alcohol – No. units per week ☐ ☐ Paan / Betel Quid / Khat chewing ☐ Previous H&N cancer ☐ Previous cancer ☐ Previous radiotherapy ☐ Immunosuppressed ☐ HIV/AIDS ☐ Human papillomavirus	
Symptoms: ☐ Pain on swallowing ☐ Mouth ulcer ☐ Unilateral deafness ☐ Trismus ☐ Sore throat ☐ Persistent hoarseness ☐ Nasal obstruction/discharge ☐ Lump / swelling in neck		☐ Bleeding ☐ Cranial nerve lesion ☐ Orbital mass ☐ Otalgia (ear ache) ☐ Oral swelling ☐ Oral white patch ☐ Oral red patch ☐ OTHER (Detail below)	
Figure 1. Please add visual extra oral sign(s) if applicable e.g. lump(s) and or swelling(s): 			
Figure 2. Please add visual intra oral sign(s): 			
Please provide other relevant information here Please describe in detail the location of lump(s) and swelling and associated history Please complete a medical history form and attach to this referral, attach additional information if required			
I have read and understand the guide for referrals of this type. Signed: _____ Signed: _____			

This form should be uploaded immediately to the FDS system through the 2 week pathway

Please note:

If you are referring your patient outside of **Greater Manchester** the process may be different. For further details please contact the relevant service commissioning team.



3.5 Patient information and support:

Information given to a patient should cover:

- What an urgent 'Two Week' referral is.
- Why the patient is being referred to a secondary care cancer service.
- The percentage of urgent 'Two Week' referrals that are cancerous.
- Which secondary care cancer service the patient is being referred to.
- How they will receive their appointment.
- The importance of attendance.
- Whether the patient can take someone with them.
- What type of tests or investigations that might be carried out and how long it will take to get results and a diagnosis.
- How to obtain further help and information about the type of oral cancer suspected.

The above information should be discussed with the patient and a summary given in a written format for the patient to take home.

To help you do this we have created a patient information leaflet that can be adapted and given to the patient following consultation (Figure 3).

Figure 3. Patient information leaflet:



Logo/Branding

Patient Information Leaflet

(Insert appropriate logo/dentist/contact details)

Date

Urgent 'Two Week' Referral

The following information provides you with a brief summary of the discussion we had today, including some commonly asked questions with regard to an urgent 'Two Week' referral.

1. What is an urgent 'Two Week' referral?

This is an urgent referral for an appointment to see a specialist when a dentist is unsure about symptoms and unable to make a diagnosis. There are many common conditions that these symptoms could be linked to. However, it is important to rule out that there are no underlying health issues including cancer.

The hospital should contact you in the next 3 days. If they have not been in touch by 3 days please let the surgery know.

2. What have you seen today?

During your dental examination today I have seen. _____

With your consent I have made a referral to. _____

3. Does this mean I have cancer?

An urgent referral does not necessarily mean you have cancer. The vast majority of patients referred urgently to a cancer service are not found to have cancer, this is very reassuring. The clinical specialist will assess you to determine if further investigations and or tests are required and will keep you fully informed.

4. Attending appointments.

It is really important that you attend all of your hospital appointments including clinic appointments and tests to ensure that you are investigated as quickly as possible without delay.

If you cannot attend your appointment it is very important that you contact the hospital to make another.

5. Support.

It is strongly recommended that you take someone with you to your appointments who can offer you support and reassurance.

If you have any questions or concerns, please contact: _____

3.6 What should the dental team and patient do?

Information given to a patient should cover:

- Make sure the patient address and telephone number including mobile number are correct.
- Ensure the patient is available within the next two weeks for an appointment.
- Ensure that the patient knows that once they have agreed the urgent appointment, it is important that they attend it, so that their care is not delayed.
- Discuss and agree that the dental practice will follow-up the patient, to ensure that the appointment is received and attended.
- Make sure that the patient is aware that the dental practice is still responsible for their regular dental care.
- If the patient is receptive to considering how to reduce the risk of cancer you can explore this with them using the information in the chapter on prevention and the contacts below. However, this will need to be determined by individual need and preferences.

3.7 Further information

Often when someone has a health scare it prompts them to think about their health and lifestyle choices, for example; smoking and alcohol consumption.

If a patient would like to know more about how to look after their health and well-being they can either speak to a health care professional and or go to:

www.cruk.org/health and or www.nhs.uk/oneyou

If the patient would like more information on cancer: Macmillan on Freephone helpline **0808 808 00 00** and or by visiting the following websites

www.macmillan.org.uk and or www.cancerresearchuk.org



04 | Patient consultation



SECTION 4 - PATIENT CONSULTATION

Summary

- Tell your patients that you are checking their mouth to rule out oral cancer as part of their check.
- Use the opportunity to give specific lifestyle advice.
- If you see something suspicious tell your patient that you are referring them to rule out cancer.

"The dentist asked if I smoked and explained why. He saw the ulcer on my tongue and referred me straight away."

SM - Oral Cancer patient

4.1 Communication guide for use by the dental team to talk about oral cancer with high-risk patients.

Patients sometimes fail to seek help for symptoms of oral cancer because of a lack of awareness about the disease. Dental care professionals can use this opportunity of a dental consultation to raise awareness. As health care professionals we are all responsible to help the general public be less afraid of cancer so that they are more inclined to engage with clinicians if they are worried about a symptom.

Please note: This is not a script but a guide for an interactive discussion between you and your patient. You can have any or all of this conversation at any point during the appointment, but we recommend you have it AFTER you have screened your patient for signs of oral cancer, so you can also communicate the results to the patient.

Results.

As part of your check up today, I looked around your mouth for signs of mouth cancer. From what I can see, everything looks fine.

Consent/ Signposting.

Because your medical history form shows you smoke & or drink alcohol regularly, I would like to spend the next few minutes to chat to you about mouth cancer? Is that okay?

**What is mouth cancer?
(ASK)**

1. Have you heard of mouth cancer before?

Yes – Please tell me what you know?

(Use active listening skills and acknowledge what they say; then go through what they may have missed)

No – Although on the increase, it is a fairly uncommon cancer that develops in any part of your mouth including your tongue, gums, lips, the roof of your mouth, inside your cheeks and under your tongue. A lot of people don't realize that you can get cancer in your mouth so we are trying to make people more aware.

Who gets mouth cancer?

2. Do you know who is more likely to get mouth cancer?

Although anyone can get mouth cancer, most people who develop mouth cancer are over 45 years of age and smoke or drink alcohol regularly. The more you smoke and drink, the more likely you are to develop mouth cancer. As you [smoke/drink/are over 45] it is important for you to be aware of mouth cancer and to be checked once a year.

Finding mouth cancer early saves lives.

3. If mouth cancer is found early, when it has just started to develop [expand if necessary], there is a very good chance that it can be cured. So it is important to learn the early signs of mouth cancer.

Signs of mouth cancer.

4. Do you have any idea what the early signs of mouth cancer are?

Yes – Acknowledge what they have mentioned.

(e.g. you're right it is often an ulcer...) and then go through what they have missed.

No – That's fine. These are the sorts of changes to look out for; a red patch, a white patch, an ulcer, a lump or pain on your lips, gums or other areas inside the mouth.

These are what I have checked for today and your mouth looks fine.

The three week rule.

5. You may have noticed that, generally, if you have any of these changes in your mouth [a red patch, a white patch, an ulcer, a lump or pain] they tend to heal within 2-3 weeks.

If something has lasted more than three weeks it means your mouth is not healing properly and it could be a sign of mouth cancer. That's when you should visit a healthcare professional to find out why. It is likely that it is nothing serious but it is always best to get things checked out.

How long do you think you would wait before getting any changes checked?

(Reinforce three week rule)

Even if you're not worried about it, or if it is not bothering you, or if you have other things to do it is important to seek help.

Who to visit.

6. If you did notice a change (a red patch, a white patch, an ulcer, a lump or pain) in your mouth that lasted longer than 3 weeks you can call the reception here to make an appointment to see me immediately or go to your GP or your local walk-in centre.

If you did find any of these signs that has lasted more than 3 weeks who would you visit: your dentist, GP or your local walk-in centre?

Who to visit.	We've found in the past that a lot of people say they really don't want to bother their dentists or GP in case it's nothing serious. We certainly would want to see any red or white patch or ulcer or lump in your mouth that has lasted more than three weeks as it means your mouth isn't healing properly and we will want to find out why — whether it turns out to be mouth cancer or not. It is important to seek help straightaway.
Beyond Oral Cancer/ CRUK TalkCancer©	7. This is true for any other symptoms even outside of the mouth. If there is something that is not normal for you that has lasted longer than three weeks, it is always best to have it checked out by your GP or another appropriate healthcare professional.
Questions.	8. Is there anything you are unsure about? Do you have any questions?
Summary.	9. Today we've discussed mouth cancer including the risk factors (being over 45, smoking &/or drinking alcohol) and possible signs of the disease (a red patch, a white patch, an ulcer, a lump or pain anywhere in the mouth that lasts for 3 weeks). You've said you would visit either the doctor or dentist if any of these signs lasts more than three weeks. Like many other diseases, if mouth cancer is found early, there is a very good chance that it can be cured. So it's good that you are aware. You can also reduce your risk of getting mouth cancer by quitting smoking, drinking alcohol in moderation and eating a healthy diet that includes lots of fruits and vegetables.

4.2 If you find a suspicious lesion

I have seen something in your mouth and would like to refer you to a specialist to rule out cancer. I will send the appointment today and you should receive an appointment to be seen within the next two weeks.

- With a risk threshold of 3% you are legitimately sending patients to 'rule out' cancer (exclusion rather than detection).
- We know that patients would rather hear the word cancer for the first time from their primary care clinician.
- Our responsibility as health professionals is to help the general population be aware of signs & symptoms of cancer and to seek help.
- NHS now advises GPs to say to every patient on urgent pathway that 'referral is to rule out cancer'.
- Talk patient through the referral process and give them the URN and patient information leaflet.

Additional information:

1. Very Brief Advice (Assess, Advise and Arrange) and Lifestyle Advice as appropriate

Please give smoking cessation and alcohol use advice to patients as normal along with appropriate lifestyle advice.

2. Barriers to seeking help (Assist).

Below are some other reasons that may lead patients to delay seeking help and how they may be addressed.

Prioritising.

Although a change in your mouth may not be as troublesome as other things, it may become serious so it needs sorting out before this happens. You have to look after yourself if you are going to be able to look after others.

Concerns about being diagnosed with cancer.

Don't panic as most red patches, white patches, ulcers, lumps or pain in your mouth don't turn out to be cancer but they still need treatment if they have lasted three weeks or more, so it is best to go sooner rather than later.

Concerns about disfiguring treatment.

Treatment for early mouth cancer does not involve major surgery and sometimes does not need surgery at all. So early detection is best. The sooner you seek help the better the treatment and outcome.

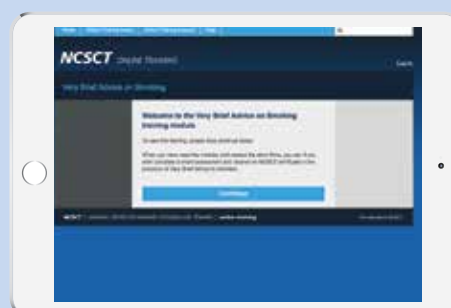
4.3. Recommended electronic learning links



Behaviour change and cancer prevention.

www.elearning.rcgp.org.uk/course/info.php?id=211

Date of publication: 2017



Smoking – brief intervention.

www.elearning.ncsct.co.uk/vba-launch



Alcohol – brief intervention in a dental setting.

In line with The UK Chief Medical Officers' 2016 guidance on low risk drinking.

www.alcohollearningcentre.org.uk/eLearning/

Date of publication: 2017



Oral cancer recognition toolkit.

Including a lesion recognition resource, referral decision guide and an oral, head and neck examination video for dentists.

www.doctors.net.uk/oct

Date of publication: 2015



05 | Dental Care during the Cancer Journey



SECTION 5

DENTAL CARE DURING THE CANCER JOURNEY

Summary

- Cancer treatments, surgery, radiotherapy to the mouth and chemotherapy affect the mouth and dental care.
- All oral cancer patients will have dental care planned as part of their treatment, some of this undertaken by restorative specialists.
- Dental practice teams will provide care for some patients with oral cancer and patients with cancers at other sites.
- Some patients will need dental treatment before their cancer treatment begins.
- Care during treatment includes managing symptoms and any infections.
- There are long term care needs for patients who have had surgery and radiotherapy.

"I couldn't swallow anything, including fluids after 12 radiotherapy treatments."

LR - Cancer patient

"I had inflammation, soreness, swelling and ulcers during treatment."

AP - Cancer patient

5.1 Introduction

General dental practitioners have an important role in the management of patients who have been diagnosed with cancer. This chapter outlines the role of the GDP, specialist restorative consultant and dental management for patients at different stages of their cancer journey, be that oral cancer or cancer at another site in the body.

5.2 Adverse effects of cancer treatment

Oral complications may be caused directly by the cancer or its treatment. Surgery can cause functional issues depending on the site and extent of surgery. Radiotherapy stops healing and repair can have significant and long-lasting effects.

Chemotherapy drugs stop cells repairing, many reduce the production of blood cells that fight infection and factors that help the blood to clot.

Oral complications of cancer treatment arise in various forms and degrees of severity.

5.3 Short term complications

- Pain & mucositis
- Dry mouth (xerostomia)
- Infection
- Functional issues (difficulty opening, swallowing etc)
- Bleeding
- Neurotoxicity



“My teeth and gums were painful during the cancer treatment and I have some longer term problems. DB Cancer patient.”

DB - Cancer patient



5.4 Longer term risks

- Dry Mouth
- Dental caries
- Trismus (difficulty opening mouth)
- Functional issues
- Osteonecrosis (dead bone)

5.5 Dental Care for patients with oral cancer

The main treatments for oral cancer are surgery and/or radiotherapy, with or without chemotherapy. If mouth surgery or radiotherapy are planned for the patient, then the dental treatment of that site will normally be undertaken by a specialist restorative consultant. However, the dental care of the rest of the mouth will be undertaken by the patient's general dental practitioner under guidance from the restorative consultant.

If patients are receiving cancer care for sites other than the mouth, then the care would normally be undertaken by a general dental practitioner. A care pathway is outlined in figure 4.

5.6 Dental care of patients post diagnosis and prior to cancer treatment

If radiotherapy/ chemotherapy is planned, the patient may need primary dental care before cancer treatment as part of their multidisciplinary treatment plan.

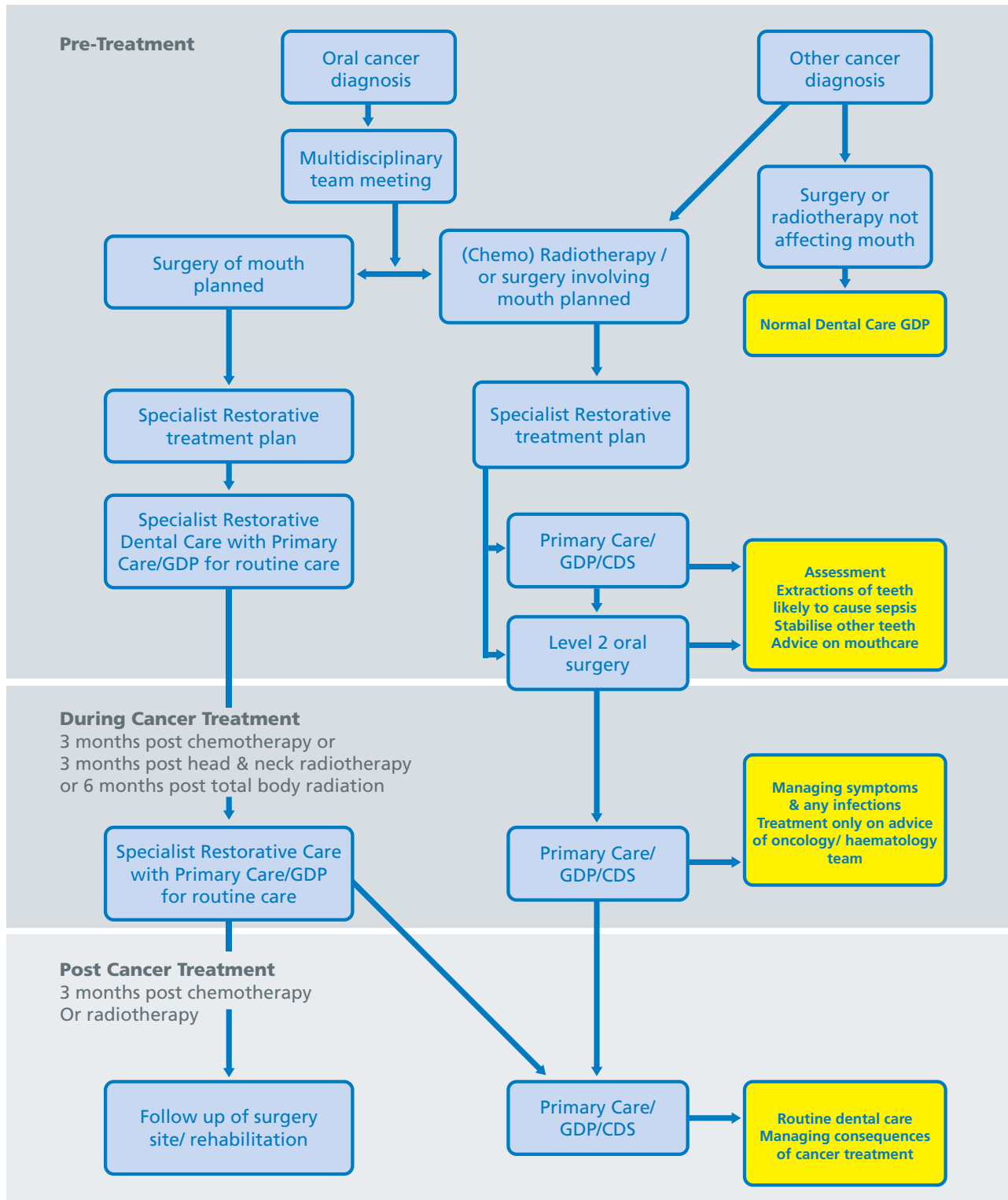
DENTAL CARE PRIOR TO TREATMENT



- An assessment,
- Removal of teeth that are likely to cause sepsis
- Stabilising other teeth and periodontal condition
- Advice on mouthcare during treatment
- Dietary advice on caries prevention
- Prescribe high fluoride toothpaste 5000 ppm in patients at increased risk of caries
- Saliva replacement if patient has a dry mouth (Not Glandosane if dentate).

This treatment often needs to be done as a priority before the start of cancer treatment. Extractions must be carried out as early as possible to ensure maximum healing and not be undertaken less than 10 days before commencing radiotherapy to the head and neck region. You may be asked to see patients and provide treatment quickly.

Figure 4 Care pathway for dental care before, during and after cancer treatment



5.7 Dental care of patients during and after cancer treatment

All patients with oral cancer will have a multidisciplinary treatment plan including restorative dental care. Restorative consultants will provide specialist dental care for the site of radiotherapy or surgery for oral cancer patients with GDPs providing the rest of the patient's dental care. Primary care dental teams will also provide dental care for oral cancer patients who are receiving chemotherapy and for patients with cancers at other sites.

DENTAL CARE DURING TREATMENT

- Advice and support to patients to manage symptoms during treatment
- Ensuring fluoride treatment- varnish and high fluoride toothpaste
- Non-invasive dental care as needed.
- Managing risks of infection

They looked after my teeth and gums during treatment and this helped manage the symptoms.

HR - Cancer patient

5.7.1 Dental infections

Dentists should be alert for the possibility of **neutropenic sepsis** in any patient with a dental infection who has received chemotherapy or radiotherapy in the previous three months. If suspected, urgently contact the patient's oncology or haematology team and the Oral and Maxillofacial dental team.

If there is no sepsis the patient can be treated in primary care. Infections should be managed aggressively with close monitoring but be extremely vigilant about follow-up and monitoring for deterioration. Before prescribing or using medicines, the dentist should consider the possibility of interactions with the patient's current cancer treatments and check with the patient's key worker or oncologist.

5.7.2 When to provide dental treatment

Surgical Dental care. Dental care is best avoided during cancer treatment where possible. If the patient has had chemotherapy or radiotherapy to the head and neck in the last three months and requires surgical intervention, then please liaise with the cancer team. Outside of these times the dental team should be aware of the possibility of oral adverse effects from cancer treatment, including risk of osteonecrosis.

Non-surgical dental care may be provided in primary care without taking advice from a specialist in patients who have had cancer treatment more than 3 months ago or for cancers at sites other than head and neck.

5.7.3 Managing common issues – Do's and Don'ts

Issue	Action
Mucositis →	• Ice chips • Mouthwashes - Difflam • Saline & sodium bicarbonate • Zinc supplements • Low level laser therapy • Avoid Honey, alcohol mouthwashes
Dry Mouth →	• Frequent sips of plain water • Saliva substitutes (not Glandosane if dentate) • Avoid sugary drinks
Decreased salivary flow →	• Recommend frequent sips of plain water. • Prescribe salivary substitute (not Glandosane)
New carious lesion →	• Duraphat 5000, Reinforce dietary advice and prevention, stabilise root caries minimally invasive/ SWE)
Soft tissue scarring/inflammation →	• Reassure & prescribe Difflam
New dental pathology →	• RCT where possible, Seek advice if had RT and need XLA
Suspected lesion or recurrence →	• Urgent Referral/ liaison with OMFS consultant
Progressive trismus →	• Refer to cancer nurse specialist/ keyworker
Worried patient Psychosomatic issues →	• Liaise with GP/cancer team/ Macmillan for support

5.8 After cancer treatment

Some consequences of cancer treatment are long term. Osteoradionecrosis is one of the most severe risks following treatment with intravenous bisphosphonates, denosumab, total body irradiation or radiotherapy to the head and neck.

Patients should be referred to oral surgery if dental surgery is needed or dental infections do not respond to treatment. Patients may have a persistent dry mouth following radiotherapy. Good preventive dental care is needed to maintain good oral health and prevent dental disease and the complications that it could bring for these patients.

"Problems can occur years later. My dentist needed to refer me back to a specialist for dental treatment because of the damage that had been done"

MS - Cancer patient

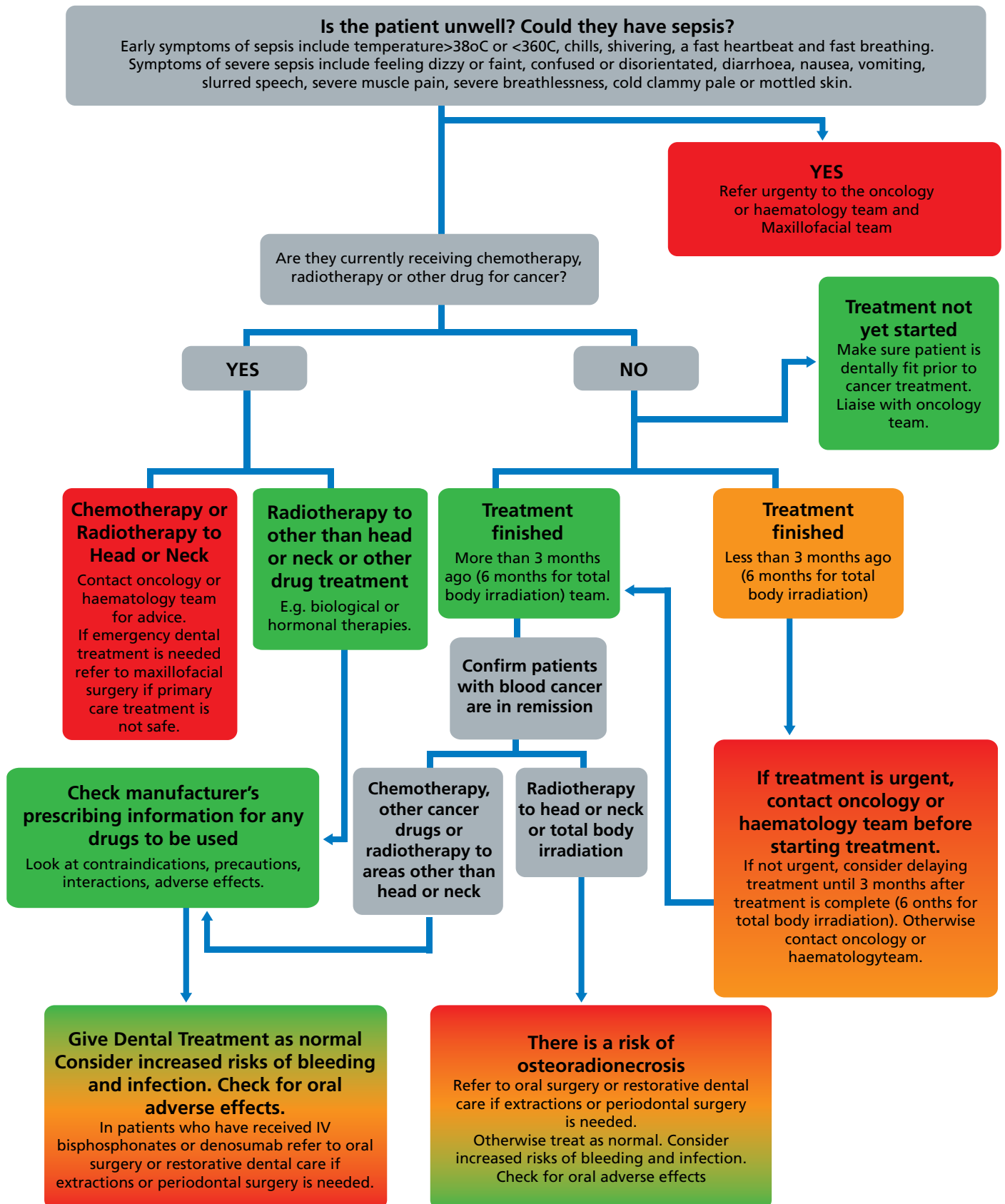
POST-TREATMENT DENTAL CARE

"They helped me to manage my trismus."

MS - Cancer patient

- Dental care post-operatively includes:
- Oral cancer screening- to check for any signs of recurrence
- Continue fluoride therapy, reinforce prevention
- Monitor dental pathology, tooth mobility
- Monitor for osteonecrosis
- Monitor for trismus

Figure 5 Clinical care pathway for cancer patients needing dental care





06 | Living with & beyond Cancer



SECTION 6 - LIVING WITH & BEYOND CANCER CHAPTER

Summary

- Cancer affects people's physical, social and psychological and financial wellbeing.
- All patients should be offered an holistic needs assessment and recovery care plan.
- The dental team can support patient's wellbeing and recovery.
- The cancer nurse is a key link to the multidisciplinary team.

"Everyone should be singing from the same hymn sheet. All patients should have information and access to a dental team."

AP - Cancer patient

This section outlines the cancer journey during and after treatment, what to expect and how primary dental care teams can help with recovery and follow up.

6.1 Patient Key-Worker/Clinical Nurse Specialist

The impact of cancer doesn't suddenly stop when treatment is over, and all cancer patients should have a 'Key-worker' to contact should they require any support or advice.

A patient's 'Key-worker' is almost always their Oncology Clinical Nurse Specialist (CNS) that they will have met at diagnosis, although patients will meet other CNSs at other Trusts as they receive treatment (surgical and/or Oncological) and may also contact these nurses for advice and support.

The patient's CNS will oversee the delivery of the Recovery Package (see below), and also be a point of contact for the patient and their families/carers should any issues or problems occur at any stage of their treatment and follow up. For example, the patient's CNS can bring forward clinic appointments in Secondary care if the patient reports issues that may represent possible recurrence; they can refer on to local services such as counselling or lymphodema management; they can arrange appointments with Restorative dental team.

If you, as their dentist see one of your patients struggling with any issues, whether they be physical, social, practical or emotional, then please ask them to contact their Clinical Nurse Specialist for assistance.

NB some patients may not recognise/remember the terms 'Key-worker' or 'Clinical Nurse Specialist'. If you ask them if they have a 'Cancer Nurse' or 'Macmillan Nurse' or a contact number for a cancer nurse that they met in clinic, or whilst they were having their surgery or radiotherapy, they should hopefully be able to confirm that they are able to contact someone. Failing that, they should be able to contact their consultant's secretary in Secondary care, who can then arrange for a Clinical Nurse Specialist to contact them to discuss any issues that they may have.

6.2 Recovery Package

Macmillan and the NHS have developed a package of interventions known to support cancer patients after diagnosis, through treatment and during follow up.

This is known as the 'Recovery Package', which aims to assess and support the patient holistically, helping health care professionals to provide targeted assistance and/or refer to local services, whilst helping to empower patients by increasing their knowledge of their cancer and how they can best look after themselves after completion of treatment. The Recovery Package has been adopted by GM Cancer and should be rolled out to all patients across Greater Manchester.

The Recovery Package consists of;

- **Holistic Needs Assessment and Care Plan.** These should be offered to patients soon after diagnosis, and again after completion of treatment. If needs or concerns are identified, a Care Plan can then be devised and agreed between the patient and their key worker to help resolve/alleviate these concerns.
- **Treatment Summary.** A synopsis of treatment received, with information about follow up, signs and symptoms of recurrence, etc. This is sent to the patient and also shared with their GP.
- **Health and Wellbeing event.** A one-off information event that patients and families are invited to attend once their treatment is completed. This usually consists of presentations by consultants/nurses/AHPs to further explain treatment and follow up plans, as well as a 'market-place' where patients can access supportive services more locally.
- **Cancer Care Review.** Each patient should be offered a Cancer Care review by their GP, within 6 months of completion of treatment.

"My dentist reacted quickly to my cancer and the team have shown sympathy and care throughout."
JM - Cancer patient

6.3 Cancer journey- stages

After a patient has received their Head and Neck cancer diagnosis, they will then proceed to the treatment stage should this be possible. After treatment has been undertaken, then patients move on to the follow-up/surveillance stage of their cancer journey.

For Head and Neck cancer patients, this is generally for a period of 5 years, where they will be seen in clinic in Secondary care on a regular basis. These appointments include a physical examination to check for signs and symptoms of recurrence; monitoring of any acute or long term side effects of treatment and dealing with the impact of these; supporting patients holistically including delivery of the Recovery Package.

For most Head and Neck patients, the frequency of follow-up appointments is as follows:

Year 1	Every 6 weeks
Year 2	Every 2 months
Year 3	Every 3 months
Year 4	Every 4 months
Year 5	Every 6 months

After 5 years of follow-up, if patients remain cancer free, they are discharged from Secondary Care and are referred back to Primary care for ongoing support. Some patients do opt for an ongoing annual review by their secondary care consultant, however.

As primary care Dentists, you will continue to see patients after discharge from Secondary Care, helping to reassure and support such patients in the community setting, along with their General Medical Practitioners. You could potentially detect late recurrences or second primary cancers, or may encounter problems associated with the late effects of cancer treatment. Please refer back to Secondary care should you have any concerns.

For certain patients, their consultant may decide to see them on a more frequent basis. As mentioned above, a patient should contact their CNS with any concerns in between their clinic appointments, as they can give advice and arrange access to a review in Secondary care at short notice if required.

"I haven't had any contact with my dentist or been offered any dental care."

DM - Cancer patient

6.4 Scans

Surveillance scans are not generally required for Head and Neck cancer patients during follow-up. There are certain tumours (such as sinonasal) that do require interval surveillance scans and the patient's consultant will discuss this with them. However, scans are frequently requested during follow-up should there be a suspicion of recurrence .

6.5 Best Supportive Care/End of Life

During or after their 5 year follow up some head and neck cancer patients will unfortunately develop local recurrence of their cancer, metastatic spread to the lungs for example, or a second primary cancer. Sometimes treatment options may be available (either with curative intent or of a palliative nature).

However, it may be that this disease cannot be treated, and these patients will be referred on to local Macmillan service for support. Again, a patient's Clinical Nurse Specialist can refer the patient to District Nurses and Community Macmillan Nurses for best supportive care in the community as things progress. Such patients may still continue to access clinic support in Secondary care should their condition allow.

Dental treatment for patients who may have limited life expectancy should be carefully considered in terms of balancing up the risk of any interventions with their quality of life; please contact the patient's relevant Restorative Dental team in Secondary care should you have any queries regarding this.

6.6 Treatments for other Cancers

Patients with other cancer in sites other than Head and Neck will undertake a similar recovery pathway. Surgery and radiotherapy don't usually impact on the mouth although chemotherapy affects the mouth as outlined in chapter 5.

Some patients receive preventive treatment after their main cancer treatment which can impact on their dental care. Patients receiving adjuvant bisphosphonate treatment to prevent recurrence of breast cancer will be at increased risk of osteonecrosis following invasive surgical treatment.

"My dental check up now includes a check of my tongue each time."

JM - Cancer patient

6.7 Psychological & other issues

Cancer can have many implications for patients and their families. Many will experience changes in their circumstances. They may have stopped working and could therefore face money worries. Some will be eligible for support with healthcare associated costs such as travel costs but may not be aware how to access this support. The patient's Cancer Nurse can provide reassurance, advice and will refer on as necessary. Local cancer support groups are available – again, the Cancer Nurse can provide information on these. Advice and support is also available through www.macmillan.org.uk.

One in five people with cancer (20%) will have experienced depression in the past year and one in ten (10%) will have experienced anxiety in the past year². This is much higher than the general adult population (5% depression & 7% anxiety in past year). This affects their quality of life, compliance with treatment and survival. Antidepressant medication can also worsen existing cancer symptoms.

People with head and neck cancer may have had surgery and altered appearance that can affect their confidence. Being seen in public, speaking and eating out can all be challenging and affect people's ability to live their life³.

Many patients and their families reported that they really appreciated when professionals took the time to ask, listen and understand the impact on their lives. They felt more confident in the care that was provided as they knew that it had been tailored to their needs.

The dental teams see patients on an ongoing basis and have an important role in asking how patients are and signposting to services that are available locally or suggesting support from the cancer nurse. Taking the time to ask, listen and understand can make a tremendous difference to patients.

“Dentists and their teams need to have more patience, understanding and to liaison with each other and the cancer team.”

LR - Cancer patient

² Pitman A, Suleman S, Hyde N, Hodgkiss A. Depression and anxiety in patients with cancer. GMJ 2018;361:K1415 accessed at <https://doi.org/10.1136/bmj.k1415>

³ Edwards D: Face to Face: Patient, family and professional perspectives of head and neck cancer care. London: King's Fund

6.8 Living with and beyond cancer

With earlier diagnosis, improvements in treatment and care, many more people are living and living well with cancer. Most dental practices will have a number of patients who have had cancer in the past. Supporting these patients to live well beyond their cancer diagnosis is important.

There is good evidence that the following factors improve recovery:

- Having more control of their care and being able to access care when they think they need it- personalised care.
- Physical activity has a positive impact on wellbeing.
- Being smoke free and healthy eating (particularly fruit and vegetables) reduces the risk of recurrence or having another primary cancer.

Primary Dental teams can aid recovery by:

- Listening to patients and taking on board their views.
- Engaging patients in their dental care and providing choices and tailored care- e.g. recall intervals.
- Knowing what cancer support services are available in your local area.
- Supporting patients to be physically active, stop smoking and eat well and signposting patients to these services as needed www.gmhealthhub.org.
- Checking with patients about their eligibility for free dental care and signposting them to Macmillan Cancer support or citizens advice who may be able to help with healthcare costs.

Dental teams have an important role to play in care of patients at increased risk:

- Providing a dental check and operative treatment where possible prior to any treatment that increases these risks
- Prescribe proactive preventive care- fluoride varnish and high fluoride toothpaste.
- Appropriate recall intervals to manage risks of dental disease.
- Being alert to recurrence or spread, particularly in the oral cavity by continuing to visually screen patients for oral cancer as part of routine care.

SECTION 7 Further guidance & useful information

Greater Manchester Lifestyle support- Smoking, Alcohol, healthy eating

www.gmhealthhub.org

Health and wellbeing for adults

www.nhs.uk <https://www.nhs.uk/oneyou/>

Health and wellbeing for families

www.nhs.uk/change4life

Smoking

www.nhs.uk/smokefree

Alcohol & other substances

www.nhs.uk/live-well/alcohol-support/NHSwww.drinkaware.co.uk

Diet and eating well

www.oneyou.gov.uk

Sugarsmart

www.nhs.uk/change4life

Support for Patients

Macmillan Cancer Support Freephone helpline **0808 808 00 00** and

www.macmillan.org.uk

Cancer Research UK

www.cancerresearchuk.org

Training resources for the dental team

Oral cancer recognition toolkit

www.e-lfh.org.uk/programmes/alcohol-and-tobacco-brief-interventions/

Greater Manchester Dental Referral system

www.dental-referrals.org/

Behaviour change and cancer prevention

www.elearning.rcgp.org.uk/course/info.php?id=211

Alcohol and tobacco brief intervention

www.e-lfh.org.uk/programmes/alcohol-and-tobacco-brief-interventions/

Alcohol brief intervention in a dental setting

www.e-lfh.org.uk/programmes/alcohol/

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