

Care of
**Head and Neck
Cancer Patients**
for Dental Hygienists
and Dental Therapists

Edited by **Jocelyn J. Harding**

WILEY Blackwell

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Edited by

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Contents

List of Contributors ix

Foreword xii

Ewa Rozwadowska

Preface xiii

Section 1 Primary Setting 1

- 1 The Early Detection of Mouth Cancer: An Initiative for the Whole Dental Team** 3
Philip Lewis
- 2 Detection and Prevention of Skin Cancer for Dental Hygienists** 14
Greg Knepil
- 3 Lip Cancer** 20
Alison E. Lowe
- 4 Smoking and Vaping** 23
Elaine Tilling
- 5 The Impact of Substance Dependence on Oral Health** 29
Teresa Servas
- 6 Human Papillomavirus as a Risk Factor for Oropharyngeal Squamous Cell Carcinoma** 36
Elizabeth Marsh
- 7 Pathologists: The Cornerstone of Head and Neck Cancer Diagnosis and Treatment** 44
Paul Hankinson and Syed Ali Khurram
- 8 Mental Health and Well-Being Pretreatment** 51
Lauren Barry
- 9 Flowchart** 53
Stephanie Wright

Section 2 Specialists, Roles, and Departments 55

- 10 The Multidisciplinary Team** 57
Lucy Baker
- 11 History of Oral and Maxillofacial Surgery** 60
Maresh Kumar

- 12 Head and Neck Cancer: Clinical Nurse Specialist Role 76**
Sonja Hoy and Joanna Rydon
- 13 The Role of the Dietitian in the Care of Head and Neck Cancer Patients 78**
Laura Kent and Hannah Cook
- 14 Speech and Language Therapy 85**
Eve Ferguson and Sarah Hartigan
- 15 The Role of the Restorative Dentist in the Management of Head and Neck Cancer Patients 91**
Michael Fenlon
- 16 The Role of the Dental Nurse in an Oral and Maxillofacial Unit 98**
Laura Holdway
- Section 3 Types of Head and Neck Cancer Treatment 101**
- 17 Chemotherapy: An Overview 103**
Helen Davies
- 18 Radiotherapy in Head and Neck Cancer 107**
Muneeb Qureshi, Brindley Hapuarachi, and Bernadette Foran
- 19 The Role of Immunotherapy in Head and Neck Cancer Management 116**
Brindley Hapuarachi, Muneeb Qureshi, and Bernadette Foran
- 20 Proton Therapy in the UK 123**
Karol Sikora and John Pettingell
- 21 Transoral Robotic Surgery 129**
Naseem Ghazali
- 22 Photobiomodulation Therapy for Management of Oral Complications Induced by Head and Neck Cancer Treatments 141**
Reem Hanna
- 23 The Hologram, a New Imaging Modality in Head and Neck Cancer 157**
Mark McGurk
- 24 Laryngectomy Care: What Is Required? 160**
Lauren Smallwood
- 25 Mental Health and Well-Being during Treatment 169**
Lauren Barry
- Section 4 Head and Neck Cancer Treatment Complications 171**
- 26 Chemotherapy and Risk Assessment in Dental Treatment Planning 173**
StJohn Crean

- 27 **Xerostomia, from the Greek (Xero = Dry, Stoma = Mouth) = Dry Mouth** 176
Leigh Hunter
- 28 **The Role of Acupuncture in Radiotherapy-Induced Xerostomia** 191
Andrea N. Beech
- 29 **Oral Ulceration, Viral Infection, and Candidosis** 194
Mike Lewis
- 30 **Halitosis** 197
Charlotte M. Carling
- 31 **Oral Mucositis** 205
Shemifhar Freytes and Alessandro Villa
- 32 **Nausea and Tooth Erosion** 211
Lucy Harrison
- 33 **Osteoradionecrosis** 213
Imogen Fox
- 34 **Mucus Secretions and Hypersalivation** 216
Lucy Baker
- 35 **Mouth Care and Quality of Life for Patients Living with Head and Neck Cancer** 218
Jocelyn J. Harding
- 36 **Obturators** 231
Rhiannon Jones
- 37 **Physiotherapy for Head and Neck Cancer Patients: An Overview** 236
Leah Dalby
- 38 **Radiotherapy: The Treatment That Keeps on Giving!** 239
Emma Hallam
- 39 **Management of Intraoral Hair Growth After Flap Reconstruction** 241
Susan Smithies
- 40 **Lifestyle Factors in Oral Cancer** 245
Mike Nugent
- 41 **Pain Management for Head and Neck Cancer Patients** 249
Roddy McMillan
- Section 5 Further Considerations, Patient Experiences and Support** 253
- 42 **Mental Health and Well-Being Post-treatment** 255
Lauren Barry

- 43 Intimacy: Advice for the Patient from a Psychologist 257**
Jo Hemmings
- 44 What Is Palliative Care? 258**
Emma Husbands
- 45 My Cancer, My Journey 262**
Roy Anthony
- 46 Life 2.0: How My Life Has Changed Since My Cancer Diagnosis 269**
Shrenik Shah
- 47 Steve's Story 272**
Steve Baker
- 48 Living with the Legacy 275**
Debbie Hemington
- 49 Look Good Feel Better 279**
Lisa Curtis
- Appendix A: Head and Neck Cancer Charities UK 281**
- Index 282**

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Foreword

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Many books portray a journey in life as their overriding theme. This book is an accumulation of real-life journeys from the perspective of all those involved in oral cancer – patients, dental professionals in general practice, diagnosticians, surgeons, radiologists, therapists, and those caring for survivors in primary care.

The creation of this book has been a journey in itself. It was born of Joss's passion for educating patients in practical oral care. Hearing the difficult stories of patients, colleagues, and family members with oral cancer inspired her to seek information about how best to help these people. This book is not only the result of Joss's enquiries but also of her ability to engage everyone concerned in dialogue about how to disseminate practical knowledge. It shows how one dental hygienist's inspiration can bring together some of the best minds in the field of oral cancer to collate information relevant to many people.

Patients with advanced oral cancer go on a devastating journey. The chapters recounting personal experiences of people living with cancer serve to remind us of the very human challenges this disease creates. Our professional responsibilities lie not only in using our skills in diagnosis and surgical, therapeutic, and rehabilitation interventions but also in developing professional empathy to support the patients and their psychological and practical needs through all stages of their journey. This book brings together these very personal aspects to improve our understanding of what it is to live with the consequences of oral cancer.

This book also gives us insights into the skills and knowledge of the primary care team and how each of the specialties contribute to the treatment and care of patients – from diagnosis and preparation for surgery, through treatment, and then rehabilitation. Each of these specialists have had their own academic and professional developmental journeys in order to help patients. In these chapters we see how these fields are developing and how we are learning more from each case.

The dental profession has an increasingly vital role to play at both ends of a patient's oral cancer journey. Early diagnosis is essential to trigger the treatment pathways as soon as possible, and soft tissue inspection is now an essential part of each dental examination. Through open collaboration and empowerment, we can use the skills of our dental teams to support oral cancer awareness and preventive initiatives to raise understanding of these conditions in the general population. This book also considers the important role of each dental team member in caring for oral cancer survivors within the setting of our general dental practices.

It has been my great privilege as a general dental practitioner to coach and mentor Joss in her drive to improve the oral care of patients. She has used her passion and her contacts to bring together this version of the oral cancer journey as it stands at present. I know that it is her mission to improve the training of medical students in this topic – may this book inspire policymakers to support her next steps in the journey of preventing these devastating diseases.

Preface

Jocelyn J. Harding

Looking back over my thirty-five year career as a dental nurse and then dental hygienist, qualifying in the Royal Navy in 1992, it is extra-ordinary to see how these roles have evolved and topics expanded. Back then the care of patients with head and neck cancer was not in our curriculum, and the cohort of patients I treated were young and fit. The career path for a dental hygienist on qualifying was non-existent, however, thankfully, with inspirational leaders, the role is now more dynamic and forward-thinking.

My passion for this particular area of care began in the early 1990s with Terry, the first head and neck cancer patient I met. I realised how little I knew about the disease and the long term implications. It was all the more shocking to me as Terry was a dear school friend of my late father, Ian. Terry and his wife, Linda, opened my eyes to the reality of being a patient living with cancer as they shared their experiences of cancer surgery and Terry's long-term complications. This personal connection helped me understand Terry's clinical journey and, more importantly, the emotional rollercoaster this lovely couple had to endure.

A few years later, my clinical skills and knowledge were further tested by Frank, a patient in general practice who needed extensive treatment– surgery, chemotherapy, and radiotherapy for a rapidly progressing squamous cell carcinoma. Frank and his wife helped me realise that we have an ongoing professional responsibility in general practice to help and advise cancer survivors, their close relatives or carers, on managing side effects, for example, limited opening and xerostomia.

I became determined to find and collate practical information for patients and health care professionals to support evidence-based preventive care and treatment pathways for head and neck cancer patients and survivors. This will allow us to improve our monitoring in general practice of the oral health of this group of patients, and consequently, reduce the risk of further dental complications such as rampant caries, extractions, and extensive osteoradionecrosis.

In 2019, as a representative of the British Society of Dental Hygiene and Therapy (BSDHT), I was able to leverage my passion for bringing people and knowledge together. At the updating of Public Health England's Delivering Better Oral Health toolkit (v4) guidelines in the prevention and detection of head and neck cancer, I was honoured to be given this opportunity to press for the inclusion of best practice in the aftercare of head and neck cancer patients at a national level. The door has been opened with a brief statement on this topic; however, I hope to convince the panel to include further information and expand vital aftercare guidance in the future.

One aspect of the care pathway for this cohort of patients rarely considered is the financial burden. Not only does the patient have psychological and physical effects, but there can be an inability to earn an income. Dental care may not be a priority before cancer treatment and the cost of rectifying dental disease and maintaining oral health can be financially prohibitive, resulting in further pain, discomfort, and rampant dental disease, which can often be prevented. I believe it is essential for every dental and health care professional to support the preventive oral care of a head and neck cancer patient before, during, and after treatment by being fully trained in how to manage the day-to-day ravages of this disease and its consequences, thereby reducing the cost to the patient and the NHS.

In 2020, I was accepted for the dental hygienist post with the Oral and Maxillofacial team in Gloucestershire Royal Hospital. This was an opportunity to further expand my knowledge in the range of complicated cases and differing dental needs alongside supporting the patients' physiological and psychological responses to the treatment in a hospital environment. As the department follows the clinical pathways set by the British Association of Head & Neck Oncologists standards 2020, I appreciate the invaluable benefit of improving the patients' outcomes through the collaborative sharing of knowledge by motivated professionals. However, the patient journey is not completed upon discharge from the hospital; the journey is only beginning.

The number of head and neck cancer patients surviving their surgery and attending general practice is increasing. As health care professionals, we must make every contact count and work towards the best patient outcome by giving up to date

preventive advice and professional care. Training undergraduate dental professionals in the early stages of their education and encouraging working collaboratively and holistically, regularly updating the latest developments in this field, will support and prepare the clinician for treating and caring for head and neck cancer patients. Science is constantly moving forward and diversifying, significantly improving outcomes in this area of cancer treatment.

As dental professionals, we must aim to support patients and their carers in living with their life-changing conditions and improving their day-to-day well-being, not only with our surgical and technical skills but also with easily understood practical information, explanations, and person-to-person communication. This personal desire to bring together and disseminate expert knowledge about the journey of head and neck cancer patients has led to working in partnership with many health care professionals across the UK and the US in the creation of this book. Reading this book's chapters, I hope you will feel supported and inspired to join us on our journey.

As Elizabeth Lank says in her book, *Collaborative Advantage*, "It goes without saying that a book about collaboration cannot be the product of one person's experience". I want to thank all of the contributors of this book who kindly said 'Yes!' when I approached them to share their knowledge and experience for this project. I am incredibly grateful as these professionals and experts supported this project at the busiest time whilst navigating through a pandemic. A pipe dream of mine would be to see later editions of this book sharing future advancements and developments, which would be wonderful.

I wish to thank Terry, Linda, Frank, Julie, Steve, Shrenik, Roy and Debbie for their honesty in sharing their personal journeys with me. I would like to thank Rob Bate, Mary Anne Freckleton, Rachel S Jackson, Emma Kent and Lisa Kyle for kindly supporting chapters with their wonderful images and figures. Finally, my immediate family, Steve, Mum, James and Emily, deserve a special mention for all the support they have given me and allowances for the time needed to complete a project such as this, along with my dear friends Andrea, Ewa, Nichola, and Sarah. My journey of learning is still ongoing as I am currently studying for my MSc in Advanced and Specialist Healthcare at the University of Kent.

Section 1

Primary Setting

1

The Early Detection of Mouth Cancer: An Initiative for the Whole Dental Team

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Early detection of mouth cancer saves lives. It doesn't only save lives, it saves the quality of life both for sufferers and everyone around them. The treatment for mouth cancer discovered early tends to be less aggressive and leads to much better outcomes than when the disease is discovered in its later stages.

The effects on the lives of sufferers, their families, and their friends are profound. Treatment itself can lead to permanent life-changing consequences that might include:

- Dry mouth
- Difficulty swallowing
- Difficulty opening the mouth
- Speech impairment
- Disfigurement
- Loss of teeth and masticatory function
- Long-term risk of osteomyelitis following extractions or other surgery after radiotherapy.

During treatment and recovery there may in addition be:

- Pain and discomfort at the surgical site
- Pain in other areas of the body where tissue has been harvested for repair
- Intensely sore mouth (mucositis).

All of these things will have serious emotional impacts and effects on mental health. These will not be confined to the mouth cancer sufferer but also will affect friends, family members, and loved ones. The formerly outgoing individual who now dreads visiting a restaurant because of embarrassment or because of inability to properly taste or enjoy food – and whose reluctance to be seen in public may even extend to family gatherings and other events – will seriously limit the ability of a spouse or partner to take part in these activities themselves.

Sufferer and partner may worry about the outcome of the disease for many years after treatment. There may be financial difficulties. Jobs may be lost as a result of the sickness. Anxiety and distress can lead to despair and depression, which seriously lower quality of life.

Primary care dental teams are uniquely placed to be instrumental in early detection. There are a number of reasons for this:

We see patients regularly. Patients' general practitioners (GPs) may see them more *often*, but crucially we always *look inside their mouths*.

Clinical team members already have a knowledge of the normal appearance of the mouth and will easily spot conditions that look suspicious.

We are familiar with the use of other early detection interventions; for example, we take x-rays, carry out periodontal pocket measurements, and sometimes use techniques such as saliva diagnostics.

All team members get to know patients. This may be especially true of non-clinical team members who are often able to immediately recognise changes in facial appearance or in the sound of the voice. It is also often the case that patients will confide in non-clinical team members things they may be reluctant to discuss with clinicians for fear that these things will be considered unimportant.

How often should we carry out examinations? As often as possible! Something that takes so little time does not have to be only reserved for check-up appointments but can easily be included in review and treatment appointments as well. Are you an orthodontic therapist adjusting an appliance? A clinical dental technician providing dentures? A hygienist carrying out a review? There are endless opportunities for a variety of team members to provide this highly important service. Mouth cancer can arise suddenly, so the more often we examine, the better.

Who needs regular exams? Everyone over the age of 16. Mouth cancer is no longer the disease of old men; sadly, we're seeing many more cases among women and the young as well as among people who do not fall into the traditional high-risk groups of tobacco users and spirit drinkers. We know other things are involved: social deprivation, age, gender, infection with some strains of the human papillomavirus, for example, but unfortunately we don't know what we don't know. There are probably other unrecognised risk factors. The bottom line is that the incidence of mouth cancer has increased by about 50% in the last 10 years. That is why everyone (including ourselves) needs regular checks.

Counselling

Dental professionals routinely diagnose conditions such as tooth decay, dental abscesses or periodontal disease. We present our findings to patients who, by and large, will accept this information in a rational way.

A suggestion of suspected mouth cancer is rather different. Prior to the clinical examination, information should be given to the patient about the importance of early detection and the actual procedure. A description of head and neck palpation is especially important for the reasons described later (see Figure 1.1).

"Cancer" is still a very scary word. It is necessary to adopt a sympathetic and supportive approach with patients and especially to advise in advance of the examination the reasons why we may want to carry out further investigations.

Words to use might include:

If we find anything unusual in your mouth, this DOES NOT MEAN you have mouth cancer.

If we're still not sure of a diagnosis, there are many possible reasons for this. That's why we sometimes ask for a second opinion.

The tests help us provide you with the very best service and allow us to identify any problems at a very early stage.



Figure 1.1 Time should be spent with the patient prior to the examination to describe the procedure and provide counselling.

While being gentle in our manner of communication, we must nevertheless stress how important it is for patients to attend follow-up appointments if recommended so that a reliable diagnosis can be reached.

Carrying Out the Examination

The examination is divided into two parts. The first part begins as the patient enters the building and is carried out by whoever meets and greets (see Figure 1.2). This will usually be a non-clinical team member.

Figure 1.2 The examination begins as the patient enters the building.



We look for obvious asymmetry: listen to their voice – is it hoarse or unusual (if so, for how long?) Are there any unusual blemishes of the skin that we should look at or question the patient about more closely? Do we have any concerns we want to relay to the clinical team?

When the patient enters the treatment room, the clinical team makes these observations again and then seats the patient.

The early detection examination begins with palpation of the head and neck to identify swellings or changes in normal texture. We need to access the tissues right down to the clavicles, so it may be necessary to ask the patient to remove or loosen clothing in this area (see Figure 1.3). It's essential we've told patients in advance that this is planned, or they may be suspicious of the procedure. We stand directly in front to view the head and neck, then, with the patient still sitting upright, we lower the chair back and look again from behind. Observing from a different angle may help to avoid missing swellings. We ask the patient to move the head from side to side. This stretches the skin over the deeper tissues, making subcutaneous enlargements more obvious.



Figure 1.3 The patient should be asked to expose the neck right down to the clavicles.

To palpate we use the pads of the fingers, not the finger tips, which have little tactile sensitivity (see Figures 1.4 and 1.5). The fingers are walked over the tissues with gentle but firm pressure to identify enlarged lymph nodes. Lymph nodes are part of the immune system. They often enlarge when an individual is fighting an infection and are then readily palpable. Infections can either originate from the organs that they drain or primarily within the lymph node itself, referred to as lymphadenitis.



Figure 1.4 Use the soft pads of the fingers to palpate.



Figure 1.5 The finger tips have little tactile sensitivity.

Lymph nodes that have enlarged because of infection tend to be soft, tender, and warm. The inflammation may spread to the overlying skin, causing it to appear reddened. The nodes return to normal when the infection is over.

Malignancies can also involve the lymph nodes, either primarily, for example, in the case of lymphoma or as a site of metastasis. In either case, these nodes are generally firm, non-tender, matted (i.e. stuck to each other), fixed (i.e. not freely mobile but rather stuck down to underlying tissue), and increase in size over time.

The major lymph node groups are located along the anterior and posterior aspects of the sternocleidomastoid muscle (SCM) and the underside of the jaw. If the nodes are quite big, they may be visible bulging under the skin, particularly if the enlargement is asymmetric (see Figure 1.6).

Examine both sides of the head simultaneously, walking the fingers down the area in question while applying steady, gentle pressure.

The posterior cervical chains extend in a line posterior to the SCMs but in front of the trapezius, from the level of the mastoid bone to the clavicle. Further nodes will be found in front of the muscle.

Additional lymph node chains include:

Tonsillar: located just below the angle of the mandible.

Submandibular: along the underside of the jaw on either side.

Preauricular: and postauricular lymph nodes in front and behind the ear.

Submental: just below the chin.

Supraclavicular: in the hollow above the clavicle, just lateral to where it joins the sternum.

It is also important to recall that swellings of the salivary glands can be an early indication of tumours, thus it is essential that the examination includes these structures.

Carefully record any unusual findings in the patient records (see Figures 1.7 to 1.14).

Some Areas of Palpation

Figure 1.7 Anterior SCM.

Position of the main groups of lymph nodes

- On either side of the major muscle that turns the head
- Under the jaw and chin
- In the hollow above the collar bones
- In front and behind the ear

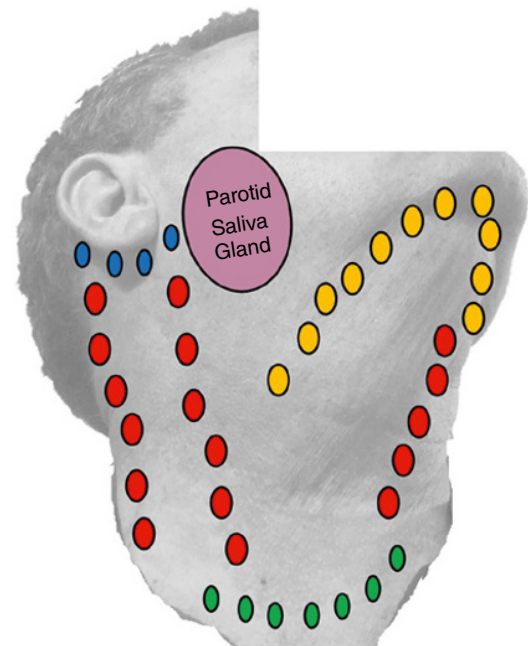


Figure 1.6 Diagrammatic representation of the position of the major lymph node chains.





Figure 1.8 Asking the patient to turn the head into your hand allows palpation under the SCM muscle.



Figure 1.9 Turning the head stretches the skin over the deeper tissues.

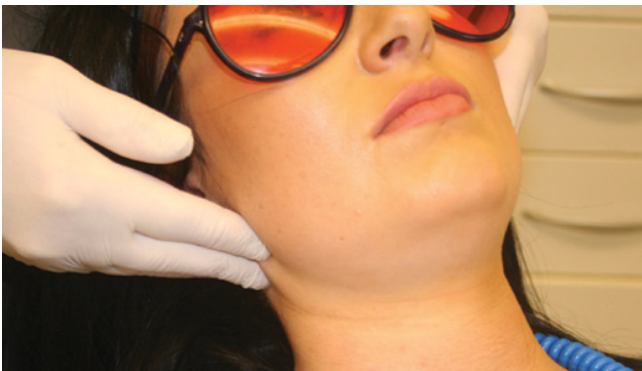


Figure 1.10 Preauricular and postauricular.



Figure 1.11 Tonsillar.

Figure 1.12 Parotids.



Figure 1.13 Supraclavicular.

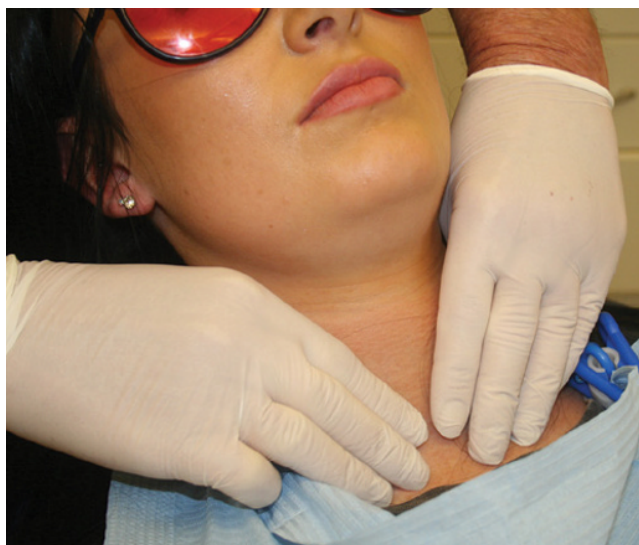


Figure 1.14 Submental and submandibular.



The second part of the examination looks at the intra-oral tissues. We need to assess the lips, labial mucosa and sulcus, commissures, buccal mucosa and sulcus, gingiva and alveolar ridge, tongue, floor of the mouth, and hard and soft palate.

During the intraoral examination, mirrors, spatulas, or even fingers may be used to hold away tissues. It is essential the areas covered by these retractors are also examined as the examination moves on (see Figures 1.15 and 1.16).



Figure 1.15 Areas of the mouth may be obscured by retraction instruments.



Figure 1.16 Be sure to examine the areas of the mouth that may have been obscured after the instrument has been moved.

With the patient's tongue at rest and mouth partially open, inspect the dorsum of the tongue for any swelling, ulceration, coating, or variation in size, colour, or texture.

The patient should then protrude the tongue. The examiner should note any abnormality of tongue mobility or position. With the aid of mouth mirrors, inspect the right and left lateral margins of the tongue.

Grasping the tip of the tongue with a piece of gauze will assist full protrusion. Palpate the tongue to detect growths. Then examine the ventral surface (see Figure 1.17).



Figure 1.17 Grasping the tip of the tongue with gauze aids manipulation.

With the tongue still elevated, inspect the floor of the mouth for changes in colour, texture, swellings, or other surface abnormalities.

With the mouth wide open and the patient's head tilted back, gently depress the base of the tongue with a mouth mirror. Examine the oropharyngeal tissues, then inspect the hard and soft palate.

Bimanually palpate the floor of the mouth for any abnormalities. Use one hand to support the floor of the mouth while examining with the fingers of the other hand. All mucosal or facial tissues that seem to be abnormal should be palpated.

Figure 1.18 Bimanual palpation.



It is important to emphasise the careful examination of the posterior floor of the mouth by placing a mirror on the lateral aspects of the posterior, non-protruded tongue to allow demonstration of this site (See Figures 1.18 to 1.22).

Any unusual findings from the examination should be recorded in the patient's records, as well as a written description recording the shape, texture, colour, and position of lesions. Identifying these on a mouth map is useful. Equally useful is a clinical photograph of the lesion. All of these methods of recording enable clinicians to reliably track the progress of lesions. Arrange to review or refer as appropriate.

Figure 1.19 Pull the back of the tongue away with a mirror to examine the posterior floor of the mouth.





Figure 1.20 The anterior floor of the mouth can be examined by holding the tongue upwards.



Figure 1.21 Hard and soft palate both need examination.



Figure 1.22 Asking the patient to say 'Aah' helps to reveal the anterior pharynx. Pressing down on the tongue with a mirror or spatula at the same time gives a better view.

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

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

All you need is a mirror, a good light source and clean fingers

1. FACE
Look for swellings you have not noticed before and inspect your skin. Turn your head from side to side, stretching the skin over the muscles making lumps easier to see.

2. NECK
Run your fingers under your jaw and feel either side of your neck. Are there any swellings?

3. LIPS
Pull your upper lip upwards and bottom lip downwards. Look inside for any sores or changes in colour.

4. GUMS
Examine your gums feeling around the gum for anything unusual.

5. CHEEKS
Open your mouth and pull your cheek away one side at a time. Look for any red or white patches. Check for ulcers, lumps or tenderness.

6. TONGUE
Gently pull out your tongue and examine one side then the other. Look for swellings, ulcers or changes in colour. Examine the underside of your tongue.

7. FLOOR AND ROOF OF MOUTH
Tilt your head back and open your mouth. Then lift your tongue up and look at the floor of the mouth. Observing changes in colour, ulcers or swellings.

What is Mouth Cancer

This is the general term given to the variety of malignant tumours that develop in the mouth, (oral cavity). The Mouth Cancer Foundation promotes awareness of all head and neck cancers i.e. throat (pharynx), voice box (larynx), salivary glands, nose, nasal, sinuses, lips and skin.

Symptoms

- An ulcer or white or red patch anywhere in the mouth that does not heal within 3 weeks.
- A lump or swelling anywhere in the mouth, jaw or neck that persists for more than 3 weeks.
- Difficulty in swallowing, chewing or moving the jaw or tongue.
- Numbness of tongue or other area of the mouth.
- A feeling that something is caught in the throat.
- A chronic sore throat or hoarseness that persists more than 6 weeks.
- Unexplained loosening of teeth.

Risk Factors

- Tobacco use is the main cause of mouth cancer.
- Drinking alcohol to excess can increase risks four fold.
- Drinking and smoking together can make mouth cancer up to 30 times more likely to develop.
- Poor diet and social deprivation is linked to a third of all cancer cases.
- The Human Papilloma Virus (HPV), transmitted through oral sex, could overtake tobacco and alcohol as the main risk factor within the next decade.
- Exposure to the sun is a cause of skin cancer which can affect the lips and face.

To make a donation or for FREE information visit
www.mouthcancerfoundation.org
Advice Line: 01924 950 950 • Head Office +44 (0) 208 940 5680
Alternatively you can email info@mouthcancerfoundation.org

Facts about... MOUTH CANCER

Mouth Cancer FOUNDATION
Awareness and Support

www.mouthcancerfoundation.org

Figure 1.23 Information about self-examination is available from the Mouth Cancer Foundation. *Source:* Mouth Cancer Foundation.

So what are we looking for? Basically, anything we find unusual. Of course there are many innocent things that make the appearance of the inside of the mouth unusual – trauma, for example; however, traumatic injuries will usually heal quickly, and if we suspect that’s what we’re looking at we can review after a couple of weeks to make sure the problem has resolved.

What we’re specifically looking for are:

- Red or white patches of no obvious cause
- Unexplained lumps
- Ulcers that don’t heal in a maximum of three weeks
- Changes in texture or sensation
- Bleeding from the mouth or throat in the apparent absence of gum disease
- Teeth that loosen in the apparent absence of gum disease
- Hoarseness of the voice
- Persistent sore throat
- Reports of a feeling of something ‘stuck’ in the throat.

If anything we find in our examination leads us to believe we may have discovered early mouth cancer, **THE PATIENT MUST BE REFERRED IMMEDIATELY FOR A SPECIALIST ASSESSMENT**. Rapid referral pathways exist in all health areas but may vary across regions. Find out how to access yours.

Patients should be encouraged to examine themselves regularly at home. Details of how to do this can be found on the Mouth Cancer Foundation website, www.mouthcancerfoundation.org (search for ‘Bite Back at Mouth Cancer’; see Figure 1.23).

A full early detection examination including palpation takes less than two minutes.

Factoring that into our routine workflow could save a life and leave us free to continue carrying out all of the other high-quality treatments our patients deserve. Every team member, clinical or non-clinical, has an important role to play. This really is a team effort.

2

Detection and Prevention of Skin Cancer for Dental Hygienists

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The Role of Hygienists in the Early Recognition and Management of Skin Cancers

Skin cancers are the most common cancer to affect fair-skinned people, and most skin cancers develop on the head and neck. Skin cancers are often slow growing, and frequently patients have visited a dental professional when their skin cancer has been present but before they have visited their GP with a concern. This makes the role of the dental hygienist important in the early detection and raising of concerns about a possible skin cancer, which should prompt a referral to the patient's GP or skin cancer specialist. Health education is also an important preventive measure against the development of skin cancers, and hygienists have an opportunity to educate their patients about risky and healthy behaviours, with particular emphasis on ultraviolet (UV) exposure and protection, self-examination, and vitamin D.

A study of patients undergoing skin cancer surgical removal in Gloucestershire, UK, in 2019 illustrated real-life evidence of the important role hygienists can play in skin cancer management. This study found that two-thirds of the patients were regular dental attenders. Of those regular dental attendees who had visited a dental surgery since the lesion had been identified, one-third had visited a hygienist. Overall, the lesion was only mentioned to 6% of patients by the dentist but was mentioned to the patient by 25% of hygienists. Following a brief educational programme, dental health care professionals felt more confident in raising concerns and discussing health advice regarding skin cancer with their patients (Harte and Knepil 2019).

Skin Anatomy and Physiology

Skin is the largest organ in the body and acts as a waterproof barrier that protects the body from external environmental hazards and prevents loss of water and other bodily substances. The skin is made from three layers called the epidermis, dermis, and subcutis. The epidermis is a thin waterproof layer mostly made of cells called keratinocytes. Keratinocytes change in character as they migrate from the basal layer to the surface, where they are exfoliated. The dermis lies just beneath the epidermis and is a tough fibrous layer, mostly composed of collagen, and contains hair follicles and secretory glands for the skin. The most superficial dermal layer is called the papillary dermis, which interfaces with the basal layer of the epidermis, and the deeper layer of the dermis is called the reticular layer. Deep to the dermis lies the subcutaneous fatty layer, which insulates the body and acts as a protective cushion. As the outermost layer of the body, the skin is subjected to environmental hazards, especially UV radiation, types A and B (see Figure 2.1).

What are Skin Cancers?

Skin cancers arise from the dermal and epidermal layers of the skin, and the most common types are basal cell carcinoma (BCC), squamous cell carcinoma (SCC), and melanoma. Other types of skin cancer exist but are less common (Table 2.1). BCC and SCC are collectively described as nonmelanoma skin cancers (NMSCs) or, more specifically, keratinocyte skin