

# The development of mouth, head and neck cancer awareness in Ireland and results of Mouth Cancer Awareness Day 2011

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## Introduction

Cancer is a very important word, especially for those who have it. Both healthcare workers and the general public are very aware of the seriousness of breast, prostate and bowel cancer, but until recently, the Irish public were generally unaware of mouth cancer. This is despite many organisations, including the Dublin Dental University Hospital (DDUH), the Cork University Dental School & Hospital (CUDSH), the Faculty of Dentistry of the Royal College of Surgeons in Ireland (RCSI), ear, nose and throat/oral and maxillofacial courses, and various patient groups trying to highlight its importance. Mouth cancer is a serious condition and the effects of the disease, its treatment and its outcome can be catastrophic, if diagnosis is late. The oral cavity and face have a very significant nerve representation in our brain for good reason – we taste, smell, see, hear, feel, breathe, drink, chew, eat and swallow. These senses and functions are frequently affected if the disease presents late. The disease and its treatment may have serious psychological effects on our patients, as the results of treatment can be debilitating and disfiguring.

Oral and pharyngeal cancer is the sixth most common form of cancer globally (all cancers = 405,300 per year), and oral cancer constitutes approximately 275,000 cases per year. More than 300 cases of cancer of the oral cavity and pharynx are reported in

Ireland every year. In Britain, the incidence of mouth cancer has increased faster than any other cancer in the past 25 years (p63). If the disease is diagnosed early the prognosis is very good, with an 80% survival rate. If the disease presents at an advanced stage, the prognosis can be as poor as 15% or less. Overall, despite all advances in diagnosis and treatment, the prognosis is 50% five-year survival.

In 2006, author Lia Mills was diagnosed with mouth cancer and she told her story at the launch of the 2011 Mouth Cancer Awareness Day (MCAD) in the Royal College of Physicians in Dublin. (An article based on Lia's speech is featured on page 89-90 of this *Journal*.) During her treatment, Lia voiced her concern at the lack of information available to the Irish public regarding mouth cancer. Something to try and improve the prognosis was required, and this led to the development of 'mouth cancer awareness'. During discussions, it became clear that an awareness campaign without informed and educated healthcare support might raise public concern without the ability to assess and hopefully reassure people. It was planned to include as many willing and informed healthcare workers (dentists initially) as possible in the campaign. These healthcare workers would require education, supportive documentation and a means to refer any

**Table 1: Symptoms and signs.**

■ A sore or ulcer in the mouth that does not heal (>2/52), especially in a smoker;
■ leukoplakia (white) or erythroplakia (red) patches inside the mouth for no known cause;
■ a new lump in the mouth/neck/salivary glands;
■ thickening or hardening of the cheek/tongue/salivary glands;
■ unexplained numbness of the lip, tongue or face;
■ difficulty chewing (limited mouth opening), swallowing or moving the tongue (fixed);
■ unexplained loose teeth;
■ persistent sore throat/hoarseness >3/52; and/or,
■ persistent nosebleeds/stuffy nose.

potential patient for treatment.

The term mouth cancer was used rather than oral cancer in order to help the public to understand, and to make it easier for dentists and other healthcare workers to explain the condition to their patients. Prevention is better than cure and the public needs to be made aware of the risk factors for mouth cancer. Smoking, especially with alcohol consumption, has been shown to be the major cause, but identification of symptoms and signs (Table 1) is essential, as non-smokers and non-drinkers have developed the disease. There have been many public health efforts to persuade people to reduce smoking and contain their alcohol intake. Diet is another important, and often ignored, risk factor, and this is being addressed through the five-a-day campaign. There remained a need to educate the public on the early symptoms and signs, and what to do if a person develops any of these symptoms and signs. People talk to their friends, their friendly pharmacist, their doctor and usually their dentist, when they have one. It is because the disease occurs in the mouth and neck that dentists must have a key role to play in the early detection of this disease, so all members of the public, young or old, should have a dentist. Like all of the healthcare team, dentists and dental hygienists need educational updates, support, information and a reliable referral process. Dentists and dental hygienists also have an important role in prevention, with regard to advice on smoking cessation, alcohol intake and diet, and the diagnosis of any 'potentially malignant lesions' such as leuko/erythroleukoplakia.

A group of mouth, head and neck cancer survivors, in collaboration with representatives from the DDUH, the CUDSH, the Dental Health Foundation and the Irish Cancer Society, came together to consider how to develop a mouth cancer awareness programme. The primary aim of the group was to raise awareness of mouth cancer as a

disease that affects an increasing number of people in Ireland, many of whom do not fall into recognised risk categories. Mouth, Head and Neck Cancer Awareness Ireland (MHNCAI) aimed to form a coherent national organisation that would include representatives from professional groups involved in oral healthcare, cancer care and health promotion, along with patients and carers. The group hoped to involve and inform the general public and cancer care providers at the primary, secondary and tertiary levels. The MHNCAI group was formally launched on September 27, 2010, with the publication of the leaflet 'Mouth, Head and Neck Cancer: what you should know', funded by the Irish Cancer Society and the Dental Health Foundation. The first MCAD was held in the two dental schools on September 29, 2010, and the results are reported elsewhere in this Journal (MacCarthy *et al.*, page 101). A total of 1,661 individuals were examined in the DDUH and 1,355 in the CUDSH, and from this group six individuals were diagnosed with a biopsy-confirmed mouth cancer. The patients with confirmed squamous cell carcinoma have all been treated. The Minister for Health and all Opposition health spokespersons were supportive of the initiative and encouraged future health programmes.

In 2011, Dr Conor McAlister, President of the Irish Dental Association (IDA), made mouth cancer awareness a major focus of his education programme. The IDA agreed to extend the mouth cancer awareness campaign to all dentists in Ireland, bringing the educational programme to all parts of the country. The concept of a second mouth cancer awareness day was launched to the dental profession at the IDA Annual Conference in May 2011. A logo was designed and work commenced on a website, designed and maintained free of charge by Think Media, publishers to the *Journal of the IDA*. A domain name – [www.mouthcancerawareness.ie](http://www.mouthcancerawareness.ie) – was registered. Information about mouth cancer in general, and MCAD 2011 in particular, was made available to the dental profession and to members of the public on the website.

Approximately 700 dentists signed up to participate in MCAD 2011. A dedicated volume of the *Journal of the Irish Dental Association* (Volume 57, Number 4, August/September 2011) was published on mouth cancer, including an article on 'Oral and neck examination for early detection of oral cancer – a practical guide (MacCarthy *et al.*, 2011), so that all clinicians might carry out examinations in a similar manner. The *Journal* was sent to all dentists on the island of Ireland, and various marketing materials were distributed by Colgate to every participating dental surgery, including information on smoking cessation, mouth head and neck cancer information, leaflets from the Irish Cancer Society and MCAD posters. In addition to the educational material on the website, a number of lectures and presentations took place around the country to educate dental practitioners about mouth cancer and the examination procedure. Lectures took place in the following areas, and the attendance numbers in brackets testify to the outstanding interest shown by the dental profession in this initiative: Sligo (20), Galway (70), Dublin (200), Cork (150), Waterford (80) and Limerick (50). These lectures were organised by the IDA and were open to all dentists, including

non-members. Lectures were presented by experienced clinicians on the signs and symptoms of mouth cancer, how to examine and what to do if concerned about the findings on examination. In Dublin, over 200 dentists attended a lecture given by Professor Saman Warnakulasuriya from King's College, London. Professor Warnakulasuriya has published and lectured extensively on the subject of oral cancer and pre-cancer, and is currently Director of the WHO Collaboration Centre for Oral Cancer in the United Kingdom. King's College represents the UK as one of three countries involved in an EU (Leonardo da Vinci) project to raise awareness among dental professionals of oral cancer screening and early detection through lifelong learning. Greece and Italy are the other two countries involved in this partnership since it commenced in 2009. As a result of MCAD 2011, Ireland (represented by the IDA) has been invited to join Phase 2 of this Leonardo da Vinci partnership – [www.oralcancerldv.org](http://www.oralcancerldv.org). Spain has also been invited to participate. The IDA offered the services of its PR company, Gordon MRM, for planning and publicity for MCAD. The event was launched on Wednesday September 14 at the Royal College of Physicians, Kildare Street, Dublin. A large number of mouth cancer patients were in attendance, along with members of the committee and interested professionals. The event attracted a large amount of print media attention and extensive coverage on radio and TV.

The awareness day was supported by an Irish Cancer Society media campaign highlighting the Society's National Cancer Helpline (freephone 1800 200 700), and encouraging anyone concerned about mouth cancer to call. There was an increased volume of calls to the helpline during the campaign.

The second MCAD (September 21, 2011) was hosted in approximately 70% of general dental practices around the country, as well as in the two dental schools. A total of 435 individuals were seen in the DDUH, and 568 in the CUDSH. In the CUDSH, screening was carried out by staff and final-year dental students under the close supervision of clinical staff. In the DDUH, students were involved in helping to co-ordinate the public through the process. Self-examination of the mouth, smoking cessation and oral hygiene advice was given by dental students and dental hygiene students. Based on the figures retrieved from forms returned by participating dentists, approximately 7,000 individuals had a free mouth cancer examination in general dental practices around the country. However, the number probably far exceeds this, as not all participating GDPs had returned their feedback forms at the time of writing (Table 2).

## Results

Information regarding MCAD was spread through media coverage, advertising by individual dental practices, posters, and an advertising campaign run by the Irish Cancer Society. Dentists signed up to participate in MCAD 2011 through the website, which was constantly updated.

Approximately 695 dentists from 515 dental practices registered for MCAD 2011. A total of 428 participant feedback forms were returned. Assuming that one form per practice was returned, this

**Table 2: Distribution of general dental practices that returned information on Mouth Cancer Awareness Day.**

Connaught	Leinster	Munster	Ulster	Total
Galway: 31	Carlow: 6	Clare: 7	Cavan: 4	
Mayo: 11	Dublin: 142	Cork: 68	Donegal: 2	
Roscommon: 1	Kildare: 23	Kerry: 15	Monaghan: 3	
Sligo: 3	Kilkenny: 10	Limerick: 18		
	Laois: 3	Tipperary: 13		
	Longford: 3	Waterford: 15		
	Louth: 8			
	Meath: 7			
	Offaly: 2			
	Westmeath: 10			
	Wexford: 9			
	Wicklow: 14			
<b>46</b>	<b>237</b>	<b>136</b>	<b>9</b>	<b>428</b>

represents a response rate of approximately 83%. However, information on actual numbers of participating dentists was not always given by group practices.

The results tabulated in Table 2 are therefore based on an 83% response rate, which is a greater than expected response.

On the day, 6,728 individuals attended general dental practitioners for a free check-up (Table 3). Of these, 68 individuals were referred for urgent examination and 371 for follow-up of non-urgent intra-oral lesions. A total of 1,652 individuals were advised to attend their general dental practitioner for dental care and smoking cessation advice. Some 213 individuals were advised to attend their general medical practitioner for issues such as hoarseness, dysphagia and weight loss. A total of 4,738 individuals were advised after examination on the day that they did not need any further follow-up, but should attend their dental practitioner for routine dental care as normal.

On the day, 568 individuals attended the CUDSH. Of these, 10 required urgent specialist opinion, resulting in diagnosis of two malignant tumours. A total of 435 individuals attended the DDUH, with five requiring urgent specialist opinion, with one malignancy detected.

Following MCAD 2011, 225 individuals were referred by their general dental practitioners on an urgent or non-urgent basis for specialist opinion, examination, advice and treatment as required (Table 4). The CUDSH received 78 referrals and the DDUH received 147 referrals. From these 225 patients, 52 biopsies were done. In the DDUH, squamous cell carcinoma (SCC) was diagnosed in eight cases

**Table 3: Number of attendees and results of Mouth Cancer Awareness Day on September 21, 2011.**

	General dental practice	Cork University Dental School & Hospital	Dublin Dental University Hospital	Total (%)
Number of attendees	6,728	568	435	7,731
Urgent referrals	68	10	5	83 (1.08%)
Non-urgent referrals	371	42	1	414 (5.35%)
Advised to attend GDP	1,652	81	183	1,916 (24.8%)
Advised to attend GMP	213	35	38	286 (3.72%)
No further treatment	4,738	400	236	5,374 (69.48%)
Biopsy		6	5	
Outcomes		2 squamous cell carcinomas – floor of mouth and soft palate 2 dysplasia/atypia 2 benign lesions	1 squamous cell carcinoma-retromolar area 2 Dysplasia/keratosis and 2 benign	

**Table 4: Number of attendees referred by general dental practitioners for additional advice and treatment following Mouth Cancer Awareness Day.**

	Cork University Dental School & Hospital (n=78)	Dublin Dental University Hospital (n=147)
Urgent referrals	13 (2 refused) – 11 seen	55
Biopsy	2	50
	Squamous cell carcinoma – tongue x 1 Lip – atypia x 1	Squamous cell carcinoma – tongue (5) buccal mucosa (1), gingiva (1), lip (1) Dysplasia (16: severe – 3, moderate – 7, mild – 6, other – 26)
Non-urgent referrals	65 (6 refused appointment) – 59 seen	92 (7 refused appointment) – 85 seen

– five tongue, one buccal mucosa, one gingiva and one lip. There were 18 cases of mucosal dysplasia or atypia detected in the DDUH, requiring regular follow-up in its joint oral medicine/oral and maxillofacial dysplasia clinic. In the CUDSH, one SCC was diagnosed and one patient with atypia in a lip requires follow-up.

The total number of malignant lesions detected, as a direct result of MCAD 2011, was 12. It is important to note that the histopathology results reported here relate to biopsy examinations in the Cork and Dublin Dental Hospitals only. We have not yet received feedback regarding biopsies taken in other centres.

### Discussion

This report provides a brief overview of the work undertaken to date by the MHNCAI group in close collaboration with the Cork

and Dublin Dental University Hospitals, the Dental Health Foundation, the Irish Cancer Society and the Irish Dental Association. From the outset, the aim of this group has been to raise public and professional awareness of mouth, head and neck cancer in Ireland. The ability to control this cancer depends largely on prevention and early diagnosis. International research suggests that primary prevention, i.e., education and behaviour modification, could produce a 90% reduction in oral and pharyngeal incidence rates simply by avoiding or drastically reducing exposures to tobacco and alcohol (Hennessey, *et al.*, 2009; US Surgeon General, 2000). Detection of potentially malignant lesions or early asymptomatic cancers, and facilitating the fast-tracking of these patients for appropriate intervention, is a key factor in reducing cancer mortality and morbidity. Research has shown that the

probability of avoiding regional spread, and the associated 50% reduction in survival, is inversely related to diagnostic delay (Speight and Warnakulasuriya, 2010; Ferlito *et al.*, 2002). The significant link between diagnostic delay and advanced stage presentation in relation to oral and pharyngeal cancer was confirmed in a recent meta-analysis by Gomez *et al.* (2011). Although the cost of treatment in personal and financial terms is significant, the use of a formal screening campaign is at present too expensive and inappropriate. However, research indicates that most oral cancers are currently detected once they become symptomatic, despite the relative accessibility of these sites and the non-invasive nature of an oral examination. National and international studies have consistently revealed a poor level of knowledge among members of the general public regarding the risk factors and warning signs associated with oral and pharyngeal cancer (O'Connor *et al.*, 2010). This suggests a clear need for educational campaigns, at local and national levels, to raise public awareness of this disease and to promote behavioural change. Mouth cancer survivors have played a very important role in educating and supporting others by speaking out about their own experiences.

The recent mouth head and neck cancer awareness days have raised the profile of this disease among members of the general public, dentists, dental nurses and dental hygienists. General dental practitioners embraced this campaign with enthusiasm, keenness and a desire to contribute. Patients who attended the screening and awareness days in the various centres received information on the risk factors, and advice regarding behaviour modification and the warning signs of this disease. Dental professionals are ideally situated to provide advice regarding smoking cessation and alcohol moderation to their patients because of the significant impact of both substances on oral and general health.

Awareness days may provide potentially life-saving intervention to those diagnosed with an oral malignancy. However, the true number of people who might subsequently benefit from the information given to the estimated 10,000+ attendees is difficult to estimate. Like ripples in a pond, the knowledge gained by one person can spread out to touch and enhance the lives of many others. This campaign has enhanced professional awareness, as evidenced by the record-breaking attendance of general dental practitioners at the lectures, demonstrating their interest in this disease and their willingness to engage fully with this campaign. The active participation of the Irish Cancer Society, the Dental Health Foundation, the Cork and Dublin Dental Schools (staff and students) and the IDA is testament to what can be achieved when everyone works together. The website developed to support participants remains active at [www.mouthcancerawareness.ie](http://www.mouthcancerawareness.ie), and should serve as a useful resource for all in clinical practice. The Irish Cancer Society has developed an information booklet on 'Understanding Cancers of the Head, Neck and Mouth, caring for people with cancer' in 2012, and this is available through their office. The Society has also recently identified a project, 'Mouth, Head and Neck Cancer: The Patient Pathway in Ireland', to help

identify the important areas to be highlighted for improvement.

As dental practitioners and dental hygienists are currently the only primary healthcare professionals trained in examination of the mouth, it is critically important that this examination is integrated into our routine daily practice, and that people are encouraged to attend regularly. It is also worth 'talking aloud' through the examination process, so that patients realise that this is an integral part of their check-up. This also provides an ideal opportunity to highlight the relevant risk factors. This type of opportunistic screening was strongly endorsed by the NHS National Screening Criteria expert panel on oral cancer (Speight and Warnakulasuriya, 2010).

Our thanks to all those who made this possible, and in particular to the patients who attended in 2010 and 2011. It is hoped that pharmacists and general medical practitioners will become involved in future mouth cancer awareness campaigns. Finally, we would like to congratulate and thank all who contributed to the success of last year's event. We hope that you will once again wholeheartedly support Mouth Cancer Awareness Day on Wednesday September 19, 2012, and will encourage colleagues who could not participate last year to consider doing so in the future.

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