



The Ben Walton Trust

EMPOWERING A PARADIGM SHIFT TO IMPROVE POLICY, AWARENESS AND OUTCOMES FOR MOUTH CANCER: A PERSONAL VIEW

MICHAEL WALTON MBE, THE BEN WALTON TRUST

For further information, please refer to: www.benwaltontrust.org

The areas that are key to producing improvements are shown in brief below.

INVOLVING GOVERNMENTS AND HEALTH BOARDS

Governments and health boards must be made aware that funding public awareness campaigns to spot mouth cancer in its early stages is an effective use of resources. Late stage mouth cancer is an expensive disease to treat. This message needs regular repeating!

AWARENESS AND EDUCATION PROJECTS ARE CRITICAL

These have to happen on many fronts and levels.

EDUCATION / AWARENESS

A dentist is unlikely to see much that is life threatening beyond sepsis and mouth cancer – so for them and medics, it is essential that they have a mandatory input as part of their training. Those in practice for some time, or who are not fully up-to-date, require continuing professional development. They need to know that almost anyone can develop mouth cancer – that the traditional risk factors do not always apply, and that mouth cancer presentation and individual outcomes can vary.

REFERRAL PATHWAY

Dentists and GPs require to have an area specialist to act as a first point of call for an opinion. They need a clear referral pathway, a pro forma agreed with with a local specialist department, as to how and when to refer urgently. Remote communities can use teledentistry to get an opinion from a specialist centre. Dentists require to carry out a full oral mucosa examination as a standard part of all treatments and to monitor changes.

DEVELOP EVIDENCE BASED GUIDELINES BASED ON BEST PRACTICE

Ensure that guidelines can be delivered and, most importantly, enforced.



The Ben Walton Trust

RAISE AWARENESS

Form action groups. Use every available official network, dental and medical groups, local and national organisations that have an interest in this disease, and patient support groups and charities.

Increase leverage on health boards and governments and use this as a platform to get local and national media coverage to increase awareness.

Agree 'the message' – it is of no use using different statistics and awareness messages, nothing confuses the public more. The message must be clear and unequivocal.

Set up, and repeat annually, Mouth Cancer / Action / Awareness / Weeks / Months.

Use personal stories from people in the public eye that have an interest in or have close experience of mouth cancer. In our culture, celebrities have high value, so use them. People identify with real stories.

Dental students have been remarkably closely involved, holding awareness days for other students, staff and the general public. The Ben Walton Trust has supplied T-shirts, information packs and other branded products with an awareness message printed on them. We have university bars that annually use our beer mats during MCAM. Medical students have been involved by the dental students and fundraise around social events. Funds raised in this way go into research, patient support and awareness events.

PRIZES

The Trust awards annual prizes for the students who have done most to increase awareness – so we tap into an altruistic streak that will stay with them throughout their careers.

SOCIAL MEDIA

Social media provides an effective way to deliver a message about the signs, the need for vigilance and action plans. It is never too young to introduce the topic, as part of a positive general health message, simply part of looking after your body, self-awareness and self-examination.

Mouth cancer is a very isolating disease. The internet is a great vehicle for patient groups as verbal communication is not problematic. With other cancers, such as breast, patient power has been just that – powerful.

DENTAL PRODUCTS

Manufacturers of dental products, ulcer treatments, toothpaste, mouth wash etc should be persuaded to include a clear (legible) warning on what to do if a condition persists and an awareness message about mouth cancer.



The Ben Walton Trust

DEVELOP ONLINE LEARNING MODULES

One of our most successful projects has been working with BMJ Learning on the online module 'Mouth cancer: recognising it and referring early'. This was developed by Professor Saman Warnakulasuriya working with BMJ clinical learning editors and peer reviewed by Professor Paul Speight. It has international uptake. Designed for medical professionals, it has also been widely used by the dental profession. It is free to access and BMJ are keen to redevelop it with a patient's section.

HIGH RISK

The 'high risk' factors can be misleading: we all know that alcohol and tobacco, particularly together, increase risk – but what about the others that you do not fully understand? It's the unknown unknowns that are also 'life threatening'.

I would suggest the message – 'Almost anyone, of either sex, young or old, smoker and non-smoker, drinker or abstainer, can be at risk of mouth cancer'. In the younger age group, traditional risk factors can be absent, calling for an open mind and vigilance.

LEARNING FROM MISTAKES

Even experienced professionals can make mistakes; regrettably, we have an adversarial and litigious culture. This leads to cover ups so that we never learn from what went wrong. An informal, non-guilt debrief in these situations may yield much of value.

"ONE ONLY SEES WHAT ONE LOOKS FOR, ONE ONLY LOOKS FOR WHAT ONE KNOWS" GOETHE

Our research shows that, in spite of increased awareness, guidelines on best practice etc, mistakes are made and delays occur. Once into treatment, generally the service is very good; it's the getting to that treatment rapidly that is the problem. Funding and support from governments etc are needed, but much can be done inexpensively, at a grass roots level. With good will, enthusiasm and drive, we can make it happen.

IF IN DOUBT – CHECK IT OUT

www.benwaltontrust.org