Mouth cancer: as a patient and as a dental professional

R. Anthony¹

Key points

Presents a personal account of a mouth cancer survivor's journey.

Describes the impact of a diagnosis of mouth cancer.

Presents the experience of treatment of mouth cancer from the patient's perspective.

Being told that you have cancer is probably one of the worst life experiences for any individual. This Opinion article presents the impact of a diagnosis of mouth cancer on a dental care professional and his family. This candid account describes how specialist knowledge can have advantages and disadvantages during cancer treatment.

I never thought that I was going to die. Never! That thought wasn't allowed inside my head and I refused to allow my family to consider it either. Even when I was told that I had an HPV-positive cancer and was introduced to a Macmillan nurse, I didn't think for a moment that it would be my end.

Of course, that isn't quite true. In quiet moments and if you didn't check yourself, you could find yourself wondering how people would reflect upon you at your funeral, who would be there and stupid things like, 'Should I write my own eulogy?' When I caught myself thinking along those lines it took an effort to pull myself back to the here and now. No, the one and only moment that it truly hit home was shortly after I had been given the diagnosis and I had left the department of oral and maxillofacial surgery and was walking back to my car. The enormity of that short 'You've got cancer' sentence really hit home. I had to stop, take a moment leaning against a lamp-post before moving on. I had attended the appointment by myself as, after hearing so many colleagues tell me that there was 'nothing sinister', there seemed little point taking my wife along for a wasted hour. Luckily, I worked in a nearby dental practice and so I made my way into the practice manager's office, a friend

of mine and had an emotional and tearful ten minutes. From there, I made my way to my wife's workplace and broke the news to her. She walked out of her work with me and we went to tell our two sons, then a 16-year-old and a 21-year-old. I told them the results of the recent biopsy and made clear to them that I wasn't going to die, certainly not from this cancer and told them that it was important that they never let the thought enter their minds either.

It had taken more than six months to get to that stage. From first feeling a lump under the angle of my jaw on the right side as I was driving down a slip road onto a dual carriageway, to getting the heart stopping diagnosis, had been, I feel, a comedy of errors. Today, nearly four years on, if I allow myself to visit this dark area, I am still annoyed, angry and frustrated about my colleagues – and I include my general medical practitioner in this, who was unwilling to refer me for a consultant opinion. I knew there was something wrong but after so many friends telling you it was a blocked salivary duct you start doubting yourself. You stop pestering as frequently as you used to as you begin to believe that you are making yourself look paranoid, a hypochondriac, stupid. You wait for this 'blocked salivary gland' to clear itself and you know, in your heart of hearts, that it will not.

In the end I bit the bullet and wrote out my own referral form to my local oral and maxillofacial surgery department and had a dentist colleague from the practice I worked in sign it.

I twice heard the phrase 'nothing sinister' at the hospital which reduced my sense of urgency and made me feel kind of silly and embarrassed that I was wasting people's time, but it did pique my curiosity as to what actually this ever enlarging lump was. With this calming 'nothing sinister' phrase ringing in my ears Christmas came and went and appointments altered to accommodate holidays so it was the end of March before I first saw the specialist and heard the news.

Life, in the space of a few minutes accelerated out of control. I remember the consultant saying 'I'm putting sinister back on the table', arranging a CT scan that afternoon and then rapidly reviewing it with me all in an hour or so. I also remember being horrified at the size of this pear shaped alien in my throat and so, so grateful that whatever was going to happen it was going to happen quickly. A right tonsillar resection under general anaesthetic was completed three days later and sent for biopsy which coincided with the passing of my aunt, my second mother, so from the outset I was not in a good place. Two weeks later I received the biopsy result; even at this stage I believed that there was nothing sinister and was still shocked when told by the consultant that it was, indeed, cancer.

Five weeks later treatment began. I had a couple of uneventful, 'what was all the fuss about,' radiotherapy sessions before my first chemotherapy session. Radiotherapy was, surprisingly, quite acceptable, especially since this was the prime cancer killer. Externally, even in the latter stages of treatment, radiotherapy

Dental hygienist, Dental Department, HMS Nelson, Queen Street, Portsmouth, PO1 3HH
Correspondence to: Roy Anthony
Email: Royjohnanthony1@sky.com

Refereed Paper. Accepted 10 August 2018
DOI: 10.1038/sj.bdj.2018.920

never really bothered me: plenty of moisturiser and a bit of sloughing in the final days of treatment and that was it. Internally? Well, that was different. Curiously, radiotherapy only became a problem in the latter stages due to the breathing tube and the mask itself. The tube was kept in chlorhexidine and rinsed before being offered to me and if it hadn't been rinsed thoroughly I had to fight against a rising nauseous feeling. Likewise the mask, rinsed with some sort of antiseptic after each exposure its lingering smell caused a quite ridiculous sense of anxiety to grow in me.

Chemotherapy, which was an all-day event wired up to pumps and enduring what seemed like endless cannulas, also passed uneventfully. Well, that is until two days after the first session when, I presume, the steroids wore out of my system and I felt drained. Each chemotherapy session passed in the same way but by the latter stages of my six treatments, my body did not seem to have enough recovery time and I just wanted to sleep, but since there was always something needing to be done this simple pleasure was denied me.

Every day other than the weekend, my wife drove me to the hospital for the radiotherapy appointment and, every Monday, joined me for my all-day chemotherapy session and watched as I was pumped full of this life saving chemical called cisplatin. Every day my family watched as my neck became redder and my mouth turned to radiated mincemeat. Spreading ulcers persisted and I developed an exaggerated gag reflex. My professional determination ensured that I continued to keep my mouth clean as best as possible; I still to this day swear by the Curaprox 5460 as the toothbrush of choice. My self-motivation was tested.

Slowly, eating became tortuous. Anything with salt, vinegar, spice, starch, mustard, chilli, curry or crunchy; anything too hot or too cold were gradually consigned to the 'I'll try that again when I'm better' cupboard. Bland became best.

It must have been four weeks into the treatment that I could not manage my poached egg and working under the strictest of instructions that I must not lose weight, I relented and turned to plunging Fortisip, a medical nutrition preparation, full time down my PEG tube (percutaneous endoscopic gastrostomy tube). Fortisip is sugar saturated with stuff in it that's 'good for you'. My stubbornness had become my enemy; I should have fed myself artificially much sooner than I did.

My problems were exacerbated by my PEG. Hindsight is a wonderful thing, but on

reflection I should have guessed that I would have problems with the PEG since the endoscopy staff were unable to halt the bleeding while I was in recovery having just had it inserted. To say that my family and I were alarmed when, a week or so later, I first saw the spreading pool of blood appear across my abdomen against the background of my white shirt is an understatement of the highest order. For my family to call on the ambulance service a further three times on my behalf, to watch them as I vomited up a couple of pints of blood, for my wife to watch her husband have his blood-saturated clothes cut off in A&E resuscitation and gamely stand by me with a large kidney dish as I vomited more blood. This took me to my lowest, lowest point. To those who regularly donate blood – thank you.

The PEG became the biggest and most worrying issue. Unbelievably, it even outshone the cancer itself. Chemoradiotherapy was going along relatively uneventfully but the PEG was a problem. The endoscopy unit replaced the PEG with a nasogastric feeding tube at the earliest moment after chemoradiotherapy had finished and much as pump feeding down a nasal tube is unpleasant, it did take away the worries surrounding the PEG. It is amazing how you grasp little victories but I do remember being pretty pleased that another trip to the endoscopy unit had resulted in a trial stoma clasp being fitted and I was now the proud owner of a nasal feed tube.

The sense of relief and the family hugs on hearing the end of treatment scan results were clear was a high but was tempered by the threat of possible recurrence within two years. Since that time my reviews have come and gone and I am now waiting for my third-year post treatment review due in August 2018. Friends have put the events behind them and rightly so, life does move on. Family can never forget as they watch me struggle to eat without having something inevitably catch in the back of my throat; variations of 'make sure dad's got a drink' at mealtimes are the norm.

There are plusses: I have lost weight, it's difficult but I am trying to put myself in a position where I can retire a little earlier, and although I have generally been a fairly relaxed character I am now even more so. I still pop in to see my colleagues who I still regard as friends. My tastes have changed and the things that I eat have changed. As I now only produce about 70% of the amount of saliva that I should eating can be a chore. I do not eat chilli anymore as even a small amount ruins my day, although I did have my first, carefully

selected, curry for three years a few weeks ago. I've even started eating rice again, something that was always getting stuck at the back of my throat. I have always enjoyed a drink although I now rarely drink red wine as the tannin dries my mouth – likewise I struggle to eat grapes. Funnily, no one asked me not to drink while I was undergoing treatment although I did cut it back to an occasional half. I used to enjoy a glass of champagne and joy of joys, I can enjoy it even more today. Radiotherapy has reduced my need to shave so diligently, although my dream of enjoying a full beard and moustache when I retire has been shattered.

Reading this you may think that I am a little bitter, even down, after the whole process. Nothing could be further from the truth since I am enjoying life to the full with a great job in a great location with wonderful people and family, friends and colleagues who supported me throughout with kind and unsolicited text messages or phone calls. To them all, I am so grateful that knowing if things had gone badly wrong they would have been there for my wife and my sons as well.

I still have my sense of humour; I run, cycle and live. My wife, my family always were everything but if possible, are now even more so. However, despite the best advice from my consultant not to become paranoid, that ever-lingering sense of concern is still with me and I doubt that I will live a day without its continuing presence.

Four months after completing treatment I emailed my local MP hoping that I may be able to add some small impetus to the campaign for HPV vaccination for boys. I no longer have the replies but I do remember the sadness that I felt at the damp negative response. I did email a second time shortly after and was again met with an extremely non-committal reply. I did not have the energy to pursue it further at the time. Instead, I chose to promote the HPV campaign from a distance. I wrote two articles in support for *Dental Health*, the journal of the British Society for Dental Hygiene and Therapy (BSDHT) and regularly shared social media campaigns. I have been open with colleagues and friends about the strong link to oral sex, speaking publicly with my colleagues at BSDHT regional groups. If just one person is helped, then it has all been worthwhile. To hear recently of the UK Government decision to support gender neutral vaccination against HPV has been late but wonderfully welcome news. Surely, it is now though that the work truly starts as we professionals have to inform the wider public.