What happens when the stories stop?

David Westgarth

Editor, *BDJ in Practice*

One of the best aspects of my chosen profession is that a fundamental part of it involves talking to people. Which, as it turns out, is great, because I love talking to people. It's how I learn. How else can you properly dissect a topic without speaking to experts, those involved and those on the ground?

One of those such jobs was between 2011 and 2015 when as part of the Oral Health Foundation (then the British Dental Health Foundation) I'd speak to patients and survivors of mouth cancer. It's one of the few forms of cancer that has a very visible side effect to it which many wore as a badge of honour (but not all) so there was this unusual situation where I'd know who I was speaking to, even though I hadn't met them before.

And then we'd chat about their history, their journey, their recovery and thoughts about the future. For anyone who hasn't done this, these stories are harrowing. Every one of these brave souls can remember in minute detail the day they were told they had cancer, how they felt in the lead-up prior to surgery, how scared they were during chemotherapy and their first meal post-recovery – it's quite something, and there's a warmth I get in knowing these people have been through hell and are willing to discuss their journeys with me.

We know that spotting mouth cancer early is crucial for beating the disease. Early detection boosts our chances of survival from 50% to 90%. Depending on where the cancer strikes, the one-year survival rate for mouth cancer is between 60% and 84%, which, after 10 years, drops to between 18% and 57%. Early detection is absolutely crucial, and prior to March 2020, patients had relatively unfettered access to dentists as and when they needed it – even though many still weren't aware of the signs and symptoms.

As we mark another year of mouth cancer action during the annual Mouth Cancer Action Month campaign, it worries me greatly that these stories may drastically drop off. We have this situation where patients still aren't aware of the signs and symptoms, human tendency is to think 'it'll go away' or 'it won't happen to me', things get worse requiring an emergency visit to the dentist, NHS practices were closed and access to urgent dental care centres could have been better, and COVID-19 forced many people to stay at home with a feeling of being uncomfortable in public. If ever there was an example of why the phrase 'perfect storm' exists, you'd think this is it.

Figures are yet to properly come out in the wash about how many cases of oral cancer were not seen or what stage patients are presenting with, and it could take years before that happens. When these data do come out, they could surprise us all and show no discernible difference, or they could be horrific. I don't envisage a situation where

dentistry finds itself in the middle ground. Late presentations will mean survival rates will tumble, and these harrowing-yet-touching stories will soon begin to ebb away. We will lose one of the most valuable learning tools we have – the 'I never thought it would happen to me but here I am' personal account. Dentists have often told me they feel they're behind the eight ball with oral cancer to begin with; risk factors including tobacco use, drinking alcohol to excess, poor diet and HPV involve patients removing aspects of their life they really would prefer not to. You also have this situation where dentists aren't exactly sure of how to approach HPV with patients. *'Excuse me, but it looks like you quite enjoy giving oral sex. That's great and I'm pleased for you and your partner, but did you know it's going to be the leading cause of oral cancer within the next decade, if not earlier? So yeh, perhaps stick to penetrative sex. And tell your other half the same if you're on the receiving end too. Thank you – I'll see you in six months. Please make an appointment with reception on your way out.'*

Not going to happen, and crucially it doesn't happen.

In the last decade, cases have risen by 58% in the UK, so these conversations need to start happening. If they don't, then they're just another element of the perfect storm, and at some point these stories will very much be a thing of the past, and we cannot let that happen. ♦

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