Mouth cancer awareness: what’s at stake?

This is a modified version of a speech given by LIA MILLS at the launch of Mouth Cancer Awareness Day 2011. Lia was one of several patients present.

You’ve heard it all before. ‘If in doubt, get checked out.’ ‘Early diagnosis leads to better outcomes.’ These slogans trip so easily off the tongue, you’d think we all know what they mean, and that they apply equally to all kinds of cancer. But do they? Are oral cancers like other cancers? I’m asking you to think about this, offering my own story as an example.

I should have known

I should have known – doesn’t everyone? – that if you have a lump or a sore anywhere and it doesn’t clear up within two to three weeks, you get it checked.

I had more reason for knowing it than most, because 20 years ago my sister, Lyn, developed a painful lump in her breast. She was told by several doctors, over the course of a year in which her health deteriorated, that her lump was benign. They put her loss of energy down to other causes. They never even did a biopsy. By the time she ended up in the casualty department of her local hospital, the cancer that had been in her breast all along had spread to her liver. She was dead three weeks later. She was 33 years old.

So, you see, I really thought I knew. And I went for regular check-ups at a breast clinic, to be sure.

But I didn’t know it was possible to get cancer of the mouth, because I’d never heard of it. When a stubborn sore developed in my cheek, the idea of cancer never crossed my mind. When a stubborn sore developed in my cheek, I did look for help for this sore, as it spread and became more painful, but the people I consulted thought the condition I had was benign and I took their word for it. A lifetime of avoiding dentists and hoping that if I ignored a toothache it would go away had prepared me for eight long months of putting up with something which, if it had been anywhere else in my body, I’d have taken to a specialist faster than you could say ‘emergency’. The irony is that, during those eight months, I sailed in and out of St Luke’s for breast checks, and never once mentioned the presence of a tumour, so close to the surface it could be seen by the naked eye. It
never occurred to me that they could be interested in what I thought was a mouth ulcer gone mad. All that time, my mouth was eating me.

The benefit of hindsight

If I, or any of my friends, had known about mouth cancer, I’d have been a lot more persistent about finding clinical help sooner than I did. As for the people I consulted, I believe they were slow to recognise the tumour for what it was because I didn’t belong to a recognised risk category: I was a woman, in my forties, a social drinker. I hadn’t smoked in eight years. I thought I’d got away with it. At a lecture given to the Irish Dental Association recently, I was very glad to hear it said that the old ‘categories’ shouldn’t be taken into account any more. Suspect lesions need to be taken seriously no matter who presents with them, man or woman, young or old, heavy smoker and drinker or neither.

Early diagnosis means a stronger chance of a cure. That’s important. But bear with me a minute, while I say that there’s a lot more at stake than that. The effects of treatment are not just cosmetic.

It’s not my intention to frighten anyone and I’m certainly not looking for sympathy, but I have a point to make and if I don’t say what I mean, I may as well not speak at all. This isn’t about me, it’s about what’s at stake. Any of the patients here today could tell similar stories. So here goes.

Consequences

By the time I was diagnosed, the squamous cell carcinoma in my cheek and gums was advanced (Stage 4) and had spread to several lymph nodes in my neck. I needed radical surgery. Here’s what the maxillo-facial team in St James’s Hospital had to do: They split my lip, and then my chin. They lifted my face open. To remove the tumour, they had to cut out some jaw, pieces of cheekbone, several teeth. They peeled away the lining from my cheek and replaced it with fat from my leg; they took the lymph nodes, muscle and nerves from my neck, where the cancer had spread. They took bone from my leg and combined it with titanium, to re-arrange my face into what it is today. And I will never, ever be able to thank them enough, for any of it. When I went into that operation we thought I might lose part of my tongue. We were worried about my eye. They saved them. I should be dead by now, and I’m not.

After surgery, I needed aggressive radiotherapy, which might not have been necessary if the tumour had been caught sooner. I needed treatment in three hospitals: St James’s, St Luke’s, and the Dental Hospital. My treatment required input from maxillo-facial surgeons, oncologists, plastic and orthopaedic surgeons, dentists, hygienists, nurses, dieticians, speech therapists, physiotherapists; I had complications, re-admissions. My GP had to mop me up several times. Off and on, I spent more than nine weeks in hospital, all because my diagnosis came late. This is not an insignificant, or even a personal, point.

Things to think about

Think of all the money and time that could be saved in the health service if a small, localised tumour could be removed, almost as cleanly and simply as a tooth.

It doesn’t take a genius to see that if you offer cancer time and space to grow, it’ll take it. Cancers of the mouth entrench themselves in delicate, sensitive, necessary places, meaning that the effects of treatment can be hard to live with. I’m not just talking about facial disfigurement, although that’s part of it. I’m talking about being able to open your mouth without a struggle. To produce a reliable quantity of saliva instead of too much or too little or none at all. The ability to chew or swallow. The sense of taste. The ability to speak or smile can be damaged, or destroyed altogether. But again, I’m not here to scare people. No two cancers are the same. Everyone’s experience of cancer is different. But we have to acknowledge that early intervention is about more than survival, it’s about quality of life.

Clearly, I’ve been lucky. Here I am, five years later, talking to you. I know people who still can’t, and never will, eat, speak clearly, or smile again. Think about that. What it would be like. How easy it is to avoid, through awareness and early intervention.

Which would you prefer, if it was you?

Your mouth

Think about your own mouth, just for a minute. What’s it for? It might not rank particularly high on your list of favourite body parts. You probably don’t think about it at all – unless there’s something there that bothers you.

Think about all the living your mouth does for you, how social it is. It’s a little like a docking station, where the self encounters the world, where they check each other out, take each other in. It’s intimate and public at the same time. You use it to express yourself, to smile, laugh, kiss, talk – how else would you communicate, or respond to other people?

Think how acutely sensitive and knowing your mouth is, how discriminating, if not downright opinionated: sweet/sour, salt/spice, hot/cold.

Imagine a life with no flavour in it. Imagine if you couldn’t move your tongue, or lick your lips, or fit your mouth around a double-decker sandwich, or ever yawn a great, big, gorgeous yawn again. Now, think about a cold sore or a mouth ulcer; how excruciating pain is, in those sensitive, silky membranes, so richly supplied with blood and nerves, so talented at conveying sensation. Think how you ignore a toothache, because who has time to go the dentist? Who even wants to go to the dentist?

Think about the relief you feel when you’ve been, when your mouth is your own again; yours to forget about. If you’re lucky. Think about it, just for a minute.

Your mouth.

How will you use yours, today?

Lia Mills is a writer and a survivor of mouth cancer. She is the author of In Your Face (Penguin Ireland, 2007), a memoir of her experience of mouth cancer.