

Performance artist, Eva Grayzel, was diagnosed with stage four oral cancer, squamous cell carcinoma on the lateral tongue, at the age of 33.

A non-drinker who'd never smoked, she endured a partial tongue reconstruction, a modified radical neck dissection, and a maximum dose of radiation therapy.

Her exceptional recovery allowed her to branch into motivational speaking, including presentations on finding strength from adversity.

She recalls: 'I was continually being told at the dental office and the oral surgeon practice I visited on several occasions over a period of nine months, "If it doesn't improve, come back," as the sore on my lateral tongue got bigger.

Why was I being asked to determine whether my condition was improving? Living with it every day, the changes were subtle. If my dentist or oral surgeon mentioned oral cancer as a possibility, I think I would have been more proactive as the sore became more painful. After eight months, I developed an unbearable earache, and was treated for water on my eardrum. I was waking up throughout the nights in tears.

I returned to the oral surgeon desperate for answers. "Your tongue is small and we don't want to cut it up unless we have to, but at this point, I guess the next step would be another

biopsy."

For the first time, after nine months of treatment at his office, I thought I should look elsewhere for answers.

A family friend told me to visit a medical centre and recommended Dr Mark Urken, chief of head and neck surgery at Mount Sinai Hospital in NYC. I took the bus into NYC that day not having an inkling that the gross sore on my tongue was cancer. He felt the enlarged lymph nodes in my neck, looked at the classic ulceration on my lateral tongue, and told me he wanted to do a minimally invasive procedure.

In a gentle voice, Dr Urken told me I had a squamous cell carcinoma. Woozy from anaesthesia, I asked if it was benign or malignant. With an apologetic tone, he said: "Eva, you are in an advanced stage of oral cancer." It was 1 April 1998, the cruelest April Fool's joke of my life. I ate well, exercised, had no risk factors commonly associated with oral cancer. I went into shock.

I had a radical neck dissection, a partial glossectomy (tongue reconstruction), and a maximum dose of radiation. I was given a 15% chance of survival.

During the 12 years since my diagnosis, I've had three negative biopsies and bilateral vocal chord polyps, but no recurrence.

For the rest of my life, I will take synthroid to counter the effect of



Eva Grayzel: 'The cruelest April Fool's joke of my life.'

compromised thyroid function due to radiation.

The winter after radiation, I had HBO, hyperbaric oxygen therapy, for an extremely painful split lip that would not heal. 28 dives were ordered to heal my lip and maximize vascularity for future complications. HBO treatments were 2 hours long, five days a week, for almost six weeks.

Six years later, I needed a molar extracted on the only side where I chew. I saw a specialist in New York, experienced with oral cancer patients. After the extraction, I was in pain for one month. I begged my doctor for more HBO since nothing else worked. He told me the 28 dives I had six years prior would last a lifetime. I complained enough that he agreed to prescribe 10 more dives. After two treatments, the pain was eradicated.

Three years later, I had an extraction of the adjacent lower molar. I started losing weight, having difficulty chewing food. I looked into options. A new bridge spanning two molars was not recommended. Dental implants were strongly discouraged by an oral surgeon specialising in radiated bone. The occurrence of ORN (osteoradionecrosis) was too great. However, another specialist told me I have a window of opportunity for implants. If bone isn't stimulated, there will be continued bone loss, and no chance for future implants. He was confident from the results of

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**Mouth cancer is diagnosed in 5,000 people annually and kills almost 2,000 people each year – that's one death every five hours. Cancers can occur in any part of the mouth, tongue, lips, and adjacent areas like the throat, salivary glands, pharynx, larynx, sinus, and other sites in the head and neck area. In its very early stages, these mouth cancers can be easy to ignore.**

**Symptoms include:**

- An ulcer or white or red patch anywhere in the mouth that does not heal within three weeks
- A lump or swelling anywhere in the mouth, jaw or neck that persists for more than three weeks
- A difficulty in swallowing, chewing or moving the jaw or tongue
- A numbness of the tongue or other area of the mouth
- A feeling that something is caught in the throat
- A chronic sore throat or hoarseness that persists more than six weeks
- An unexplained loosening of teeth with no dental cause.

# News insight

## The Blue Ribbon badge appeal

**Make a difference – get the practice the official Blue Ribbon Appeal kit.**

**Your kit will be posted out to you and will include:**

- One collection box
- 25 x enamel blue ribbon lapel badges
- An official Mouth Cancer Action Month poster for your waiting room
- Full set of instructions.

**You can either sell the badges and retain the money – or give them away to help raise awareness.**

**These striking badges play a central role in the campaign – sparking questions, debate and awareness.**

**Display your collection box at your reception desk**

**Engage patients and customers to discuss mouth cancer**

**Collect £1 per badge from patients as a suggested donation**

**Thanks to your support, 75,000 Blue Ribbon Appeal kits have been distributed in the past two years, raising funds to:**

- Set up and maintain the [mouthcancer.org](http://mouthcancer.org) website
- Create hundreds of media stories reaching an audience of 90 million a year
- Launch the campaign from the House of Commons
- Lobby Government on anti-smoking legislation and oral screening programmes

**Make a donation and receive your appeal kit and help fight cancer now!**

**I wish to donate £\_\_\_\_\_ to the campaign and receive a Blue Ribbon Appeal kit with 25 badges (suggested minimum donation £25)**

**Pay by either debit card, credit card, cheque**

**Use one of the methods below to order your 2010 Blue Ribbon Appeal kit.**

**Phone: 01788 546365**

**Fax: 01788 541982**

**Email: [bluebadge@dentalhealth.org](mailto:bluebadge@dentalhealth.org)**

**Web: visit [www.mouthcancer.org](http://www.mouthcancer.org)**

a cone beam X-ray that my bone was dense enough. Luckily for me, I had three implants, three years ago, and they were all successful.

After surgery, my head hung to the left. I couldn't straighten it. I found a myofascial neuro-muscular therapist, who gently worked to release scar tissue adhesions.

I credit much of my range of motion to those regular neck treatments. Because the left SCM was removed, I push my head up with my hand when getting out of bed; I catch my head when the car stops short; support my head when leaning back. I get a cramp in my neck when I shave under my arms; I experience severe itching along the length of my neck scar when I eat anything remotely spicy.

However, I've adapted to all these changes without a problem.

### Dry mouth

Dry mouth is more complicated. At the beginning, my mouth was SO dry, I had to practically pry my mouth open to moisten it with water. Over the years, my saliva production increased. I can make it through some nights without drinking if I sleep with my mouth closed. Quite a challenge, but possible! If I wake up during the night feeling dry, and my mouth is closed, I roll onto my left, and think saliva. Just enough drips down from my right salivary gland that was spared during radiation. Still, I always have a spill-free water bottle in bed with me so I can take a sip without physically lifting

my head.

It's amazing that, even though I only chew on the right, the left side is grimmer due to lack of saliva. Before bed, I brush, floss, stimulate, proxi-brush, irrigate, and finish it off with Prevident, a flouride treatment. My surgeon was hoping I would regain feeling on the grafted side of my tongue, but I have not. It feels like novocaine does. The graft used to be very white, since it came from the palest skin on my body.

When talking, it looked like I had a big wad of gum on that side. Now, the colour adapted to its environment, changing from pale white to pink... a refreshing change for the interior design.

If my cancer was diagnosed early, it would have been seven days from surgery to recovery. Instead, seven months of my life passed in surgery, treatment, and recovery. It was followed by repercussions of trauma to my children. It continues with a lifetime of dental complications, numerous doctor appointments and tests, health scares, occasional ringing in my ears, sensitivity in my eyes to sunlight and quality of life compromises.

Many times I asked myself, "Why me?" A friend gave me an answer: "Why NOT you?" Now, I tell my story professionally. It is more than a mission to educate, but a tribute to those that came before me, and an obligation to those that will follow.

During radiation, when I was teetering on the tightrope between life and death, I thought good and hard about how I would be remembered. I would not be remembered for taking my children to ballet and soccer, but for how I made a difference in other people's lives.

If you can save one life in your entire career by performing oral cancer screenings on everyone, and detecting it early, wouldn't it be worth it?

Eva Grayzel's upcoming speaking engagements include Tripler Medical Center Dental Symposium in Honolulu, Arkansas State Dental Association Meeting, University of Michigan Continuing Dental Education. For more information, visit [www.EvaGrayzel.com](http://www.EvaGrayzel.com).