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# TONGUE CANCER WHAT HAPPENS NEXT?



■ **Figure 1: Biopsy**

*I have recently learnt that no matter your background, or station in life (recent royal events back this up), half of us will get a cancer diagnosis<sup>1</sup>, whether or not we are intellectually prepared! When I heard those life changing words: ‘...your results have come back with cancer cells present...’ I was intellectually prepared. My background in pharma sales and marketing, including a stint as an oncology product manager, meant this was a familiar area; adverse events, survivorship curves and treatment regimes, were all part of daily discussions. However, when it happens to you...!*

A biopsy (Fig. 1), results and my treatment options quickly followed. However, what was never discussed, or if it was, I missed it, was living with and beyond cancer after all this specialist activity finished.

I was so grateful that my odd mouth ulcer had been caught early – thanks to my dentist who had fast tracked me into the head and neck cancer team. My larger than usual mouth ulcer turned out to be squamous cell carcinoma. A biopsy and the consultant treatment plan preceded a ten-and-a-half-hour operation for a partial glossectomy and left neck dissection. The whole experience was completely horrible - necessary and I thanked them for it, and meant it - but horrible!

Having spoken to many head and neck cancer patients through my association with The Swallows Head & Neck Cancer Charity<sup>2</sup> it turns out that, for obvious reasons, there is a huge focus on treatment and immediate recovery. Was there any discussion about living with the aftermath of all this specialised treatment? Not really. I was just happy that

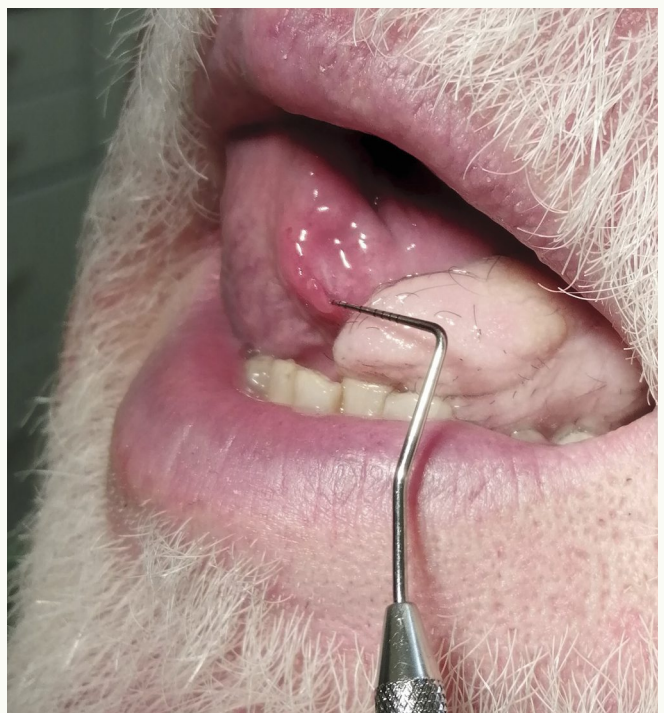
my tongue cancer had been caught early, I was in the system and they would look after me. They did. My cancerous cells had been cut out and I now had become accustomed to this new normal: a piece of my wrist grafted onto my tongue (Fig. 2), a scar on my neck and railroad track scar on my left arm from the forearm flap procedure (Fig. 3). My taste buds were all over the place and I could not feel the left side of my face. Over time this turned into odd tingling sensations which only now, six years on, are disappearing.

## Why did no one tell me about this stuff?

I would have liked to have been put in touch with a past patient who had been through a similar journey. I understand not everyone wants this, one of my mates who had prostate cancer did not want to know anything – “...just do it!” was his coping strategy. With my background I needed to know everything and fix it. This is why, along with another past patient we set up a local branch of The Swallows Head & Neck Cancer Charity where new and existing head and neck cancer patients, and their carers can talk to each other, share their journeys and learn how to cope.

The Swallows charity supply sample boxes, free of charge, to local head and neck cancer teams. Patients can try products

■ **Figure 2: Skin graft**





■ **Figure 3: Forearm flap dissection**

to help them with such problems as dry mouth and the after effects of radiotherapy. It will come as no surprise that mental health is a real problem for some patients, as the surgery and radiotherapy can be visibly disfiguring and impact badly on speech.

A main role in my work required me to give presentations so I was terrified when I heard myself talking differently as a result of my tongue reconstruction. I got through this, more in my head than anything, but real nonetheless, and I now give talks on the head and neck cancer patient's journey. For those who need to talk to someone who 'gets it', and when they want to talk, The Swallows has a 24/7 helpline<sup>3</sup> for anyone impacted by head and neck cancer, especially for those moments when it all gets too much and they need someone to talk to who has been on this journey.

## Dry mouth

Up to 78% of H&N patients who have had radiation therapy suffer from xerostomia.<sup>4</sup>

When a patient is telling you about their dry mouth as a result of surgery, radiotherapy or chemotherapy, it is important to remember it is the journey they have been on that has led to this discussion with you, their clinician. Be mindful when you are looking after our mouths and ask us about dry mouth. Some of us might need coaxing to open up about our issues. Patients with radiotherapy induced hyposalivation should be referred to nutritionists and dental clinicians should monitor them for mouth infections.<sup>5</sup>

In the UK rates of head and neck cancer are on the rise. Since 1990, Cancer Research UK has reported<sup>6</sup> incidence rates have increased by around a third overall, with rates in women increasing by almost half again and in men by a fifth. While head and neck cancer is the 8th most common cancer overall it is 4th most common in men. Us men are not generally that good at spotting these things, odd lumps, changes in taste, so when we do see you bear this in mind. Talk to us about smoking, drinking and the other things on the list below.

A big advance in head and neck cancer prevention occurred when the UK Government recommended HPV vaccination

for boys. Human papilloma virus vaccines<sup>7</sup> are now available for boys as well as girls of school age with the aim of reducing this risk factor. Vaccinating boys and girls at school against HPV aims to significantly reduce the incidence of ovarian and head and neck cancers.

## Be vigilant

Symptoms of dry mouth in head and neck cancer patients<sup>8</sup> include:

- Constant dryness and a feeling of stickiness in the mouth
- Difficulty swallowing or speaking
- Sore throat and hoarseness
- Increased thirst
- Bad breath
- Altered taste sensation
- Difficulty wearing dentures
- Oral infections such as thrush or yeast infections

On a recent Swallows virtual support group meeting I asked attendees how they cope with a dry mouth and, the other common condition, oral mucositis, where the mouth is sore and inflamed from chemo/radiotherapy. As radiation burns its way through tissue it can damage that tissue resulting in inflammation, soreness, loss of taste and cause dry mouth symptoms like thick sticky saliva and also a lack of saliva. Teeth may have been removed, jaw lines remodelled and tongues grafted or even removed. It is no surprise that the incidence of dry mouth is common and maybe the result of a number of underlying causes.

Xerostomia for head and neck patients is often permanent - try eating a dozen dry crackers with only sips of water to wash them down to get some insight into what permanent dry mouth feels like! A healthy mouth has active saliva, with a pH of between 6.7 and 7.4 and a normal production of saliva around 1-2ml/min when eating and talking, and around 0.3-0.4ml/min at rest. Without an adequate saliva flow to wash away food particles and neutralise acids produced by bacteria

patients can find it challenging to chew, swallow and digest food properly which could lead to malnutrition and weight loss. Hyposalivation<sup>9</sup>, when stimulated salivary flow is less than 0.5ml/min (dry mouth), can lead to dental caries, acid erosion, oral candidiasis, halitosis and altered taste.

My tastes changed: hot spicy foods gave way to more umami flavoured foods (Indian to Chinese); red wine became dry rose - there's now always a Pinot Grigio box to hand in my fridge – small win!

## Sjögren's syndrome

As clinicians, you are familiar with this autoimmune disease which may be linked to genetics and/or hormones, of which dry mouth is a common symptom.<sup>10</sup> People with Sjögren's syndrome may also have additional autoimmune conditions, such as rheumatoid arthritis or lupus. Other symptoms include dry eyes, dry skin, vaginal dryness, rashes and swelling between the jaw and ears (swollen salivary glands). Recommendations for patients to minimise the dry mouth element of Sjögren's syndrome are the same for dry mouth resulting from head and neck cancer treatments (surgery/chemotherapy and radiotherapy)<sup>11</sup>:

- Cut down alcohol
- Stop smoking
- Practice good oral hygiene including brushing teeth with a fluoride toothpaste twice a day
- Avoid sugary food and drinks
- Try sugar free gum or suck on ice cubes
- Use lip balm if prone to cracked lips
- Have a regular dental check up – at least every six months
- Check your other medications, the patient information leaflet, to see if dry mouth is listed as a known side-effect

## Practical advice

On a more practical note, the meeting attendees had a range of strategies, some idiosyncratic, to handle their dry mouth issues. Many have water bottles to sip from, crushed ice was often recommended by head and neck cancer teams but clearly this is not a practical long-term solution. Another patient had taken the time to create and mix his own solution based on xylitol as lack of sufficient teeth meant xylitol chewing gum was not an option. Water flossers were used by some as a gentler way to clean sensitive mouths, as were humidifiers. De-caffeinated tea was preferred as it appears to be less harsh. A dry mouth at night was commonly considered agreed as more bothersome.

It was clear from this discussion that one size does not fit all. Dry mouth also has a psychological component and in my opinion should be seen as a holistic problem rather than a mouth problem. For example, a common observation was, 'I don't go out to eat anymore.' What does that do for socialisation? One lady had complained to her doctor that she suffered from pain at the first bite of a meal and was offered paracetamol! In your roles as clinicians, even a small win can have huge benefits for your patients.

On the Swallows virtual meeting another patient told us about First Bite Syndrome<sup>12</sup> (FBS). New to me, I've since 'Googled FBS' and it is a thing. For that patient, on that Wednesday night, you should have heard the relief in her voice - just hearing that these symptoms were a recognised problem and had a known medical term made all the difference. It wasn't all 'in her head'! We helped provide that patient with the tools to go back to her GP and be taken seriously.

The prevalence of FBS is about 9.6% and usually considered as a post operative complication in head and neck cancer. I also heard about prescription treatments like Pilocarpine<sup>13</sup> which works on muscarinic receptors to stimulate salivary gland function. There was a discussion around the side effects of Pilocarpine, some based on the known adverse events such as sweating and flushing and one which I have researched that had no basis on known facts – no data (so not reported here). This flags up a warning to all health care professionals: help educate your patients to distinguish between fact and fiction, between useful researched products and anecdotal stories which do not stand up to scrutiny. Your role as a HCP is crucial to help patients navigate the AI and fake news world we all inhabit.

Patients spend a lot of time talking about how to deal with dry mouth. There is no one size fits all solution. Why not just recommend water? Water is a temporary answer, it could wash away any saliva leaving the mouth vulnerable to oral disease. Dry mouth patients are not dehydrated (not withstanding other conditions) and water can of course increase the frequency of toilet visits. Sipping water can help, but is not a solution (pun intended!), gels, creams, rinses and sprays are often better suited as they are formulated specifically for dry mouth, especially where they contain matching enzymes. Your patients may not be aware what is available to help them. Oralieve<sup>14</sup> have a useful range of moisturising mouth sprays and mouth gels replicating the same natural enzyme system found in saliva; Xerostom<sup>15</sup> mouth spray, the Biotene<sup>16</sup> range, Xylimelts<sup>17</sup> and Dr Heffs<sup>18</sup> Remarkable mints (containing Xylitol) are all available to name a few, so one or a combination should be able to provide some dry mouth relief for your patients.

When you are seeing patients who are living with and beyond head and neck cancer please understand that the journey they have been on is often long, complicated and can have had a severe impact not only on their physical appearance but also their psychological well being. There are four questions to ask:

- Does your mouth usually feel dry?
- Do you regularly do things to keep your mouth moist?
- Does your mouth usually become dry when you speak?
- Do you get out of bed at night to drink fluids?

These four questions have been clinically validated to identify 75% of all dry mouth sufferers<sup>19</sup>. Please use them - we need your expertise.

As a head and neck cancer family of patients, we have learned to live with some frankly nasty side effects from our treatments, so as dental hygienists and therapists, when you are looking into our mouths ask us about common conditions



like dry mouth, we may need a prompt to talk about this stuff. Research the products available and talk to us about them, we will listen.

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Reluctant tongue cancer patient

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