

Jon's Story: My Experience with Oral Mucositis

My name is Jon Organ and I live in south London, England. I have 4 grown up children and 11 grandchildren. I have worked in construction my whole life and, for the past 7 years, I have run my own business as a consultant advising on construction and Health and Safety.

Around 2 years ago, I had been having issues for many months with my pancreas. I attended a PET scan to check for pancreatic cancer. It was negative thankfully, however on the 16th November 2022, I attended a clinic where I was immediately diagnosed with laryngeal cancer (cancer of the voice box). After a whole host of scans and tests that followed soon after, I was diagnosed with stage 4, and by that point the cancer was now also in the thyroid gland. A total laryngectomy was the only course of action with 84 lymph nodes and thyroid to also be removed. I would forever breathe through a neck stoma.

Treatment after surgery

After 11 hours of surgery to remove my voice box, thyroid gland and lymph nodes, my treatment included radiotherapy Monday to Friday for 6 weeks, with chemo on week 1 and 5. The side effects from surgery were real and still there during radiotherapy. I was coughing a lot - suction machines and nebulisers were basically keeping me alive. I could barely speak, my breathing was poor and swallowing was an issue. What a mess I was in.

I had a 3 hour round ambulance ride to and from the hospital for radiotherapy. Because I had an altered airway, I had to have an ambulance. Between the waiting time for transport and the treatment, this took up most of the day, every day.

Radiotherapy was horrible, barbaric - I swear it almost killed me. At the beginning of treatment and radiation mask fitting, I was very claustrophobic. By the end of treatment, my breathing stoma shrank and blistered bad. I was burnt badly on my neck (it is like getting the worst sunburn every day over and over).



I felt that access to treatment for radiotherapy side effects was so limited – I asked for cream for my burnt neck and waited 6 days before getting anything, asked for mouth spray for sores but was given something that just did not work. I also requested help for my mental health however the waiting list was so long.

Effects of Oral Mucositis & GelX

On top of that, I got a terrible dry mouth with sores and swallowing got harder and harder. The stoma was becoming a major issue, burning and swelling. The mouth ulcers and dry mouth really got me down and ice cream smoothies were all I could eat. The pain was unbearable.

That was until I discovered (as a gift by Swallows charity) GelX Oral Spray. Wow, this really helped me. It was unbelievable to have a product that actually works and helps. I sprayed three times a day directly onto the cuts and sores in my mouth and it really helped.

For me personally, I noticed the real difference after about a week. If I had been using it before radiotherapy and chemo started, or from day one of treatment, I am sure the impact would have been there from the start. After about a week of using I started to eat and drink again, and I actually gained weight through my treatment!

In the first couple of weeks before I was given GelX, I lost weight. By the end of week three, once I had been using GelX, I started gaining weight. I used to weigh in every Monday and the dietitian commented that I must be the only person in history going through rads and chemo to gain weight. "That's GelX for you", I replied. Without it I would have lost more weight and, been more depressed and the journey would have been so much harder.

Something so small that can help so much is incredible really. It allowed me to recover much quicker and return to a normal(ish) life. Where I would have been without it, I honestly do not know.

To be totally honest, the journey was hell in every possible way and I went through it bad. I will take certain gains through my experience. I now have an Instagram blog Facebook support group and a website www.lifeafterlary.co.uk that helps patients going through similar experiences.

