

John's Story

Life after laryngectomy: Learning to live without a larynx



My cancer story began in February 2009 when I had a sore throat. Like most people I did nothing about it and at the time I didn't realise how severe it would turn out to be.

It wasn't until 4 months later that I had started to question whether this could be something far more serious so I finally went to see my doctor. He quickly referred me to the hospital where the specialist consultant diagnosed me with throat cancer.

My wife struggled to process the news, but for me it was no shock as I had a feeling that something wasn't right for a while. The first step in the treatment process was to try laser and radiotherapy. I had 15 rounds of radiotherapy and it wasn't until my final 15th session that I felt a severe pain due to the treatment. Unfortunately, neither of these treatments worked, so in January 2010 the decision was made to have a total laryngectomy and neck dissection.

The healing process was slow, both physically and mentally. It was difficult to recover and adjust to a life after my laryngectomy. There was a lot of swelling around the neck; it was extremely sore and painful but my wife was there with me every step of the way. It's easy to forget that partners suffer as well - my wife saw the toll each stage took on me especially after the surgery. It was especially difficult for her to see me in pain and with extensive neck swelling.

The hardest part for me was having to endure 3 months without talking due to extent of the swelling. Talking is such an important part of who I am and how I express myself that I found it

extremely hard to be without my voice.

"After the surgery my wife became my care giver until I was strong enough to start becoming more independent."

Once I had recovered from the surgery I worked with my Speech and Language Therapist (SLT) to try and gain my voice back - testing many different valves with no success. With nothing left to lose we attempted one final type of valve, and just like that I spoke! I remember jumping up and hugging my SLT. To be able to talk again was everything. I can't express how overjoyed I was to finally get my voice back. My wife was in tears, after so much time we could communicate easily with each other.

A lot has changed since having a laryngectomy. I have had to learn how to live without a larynx, which has meant many new changes to my day to day life from understanding the types of food I can eat to coming to terms with not being able to smell. I have had to acquire a clear routine around caring for my stoma and how to clean the valve. What other people take for granted, I can't. I have to be very careful about what I'm doing.

In the beginning, one of the biggest challenges was going out in public because people do stare. I learnt over time to not let this bother me and I've learnt to not let the situation dictate how I feel.

It can seem a daunting prospect to adjust to a new way of living but there is a lot of support out there from your assigned specialist nurses, dieticians and patient groups. My advice to others is that there is always someone to talk to. It is easy to become lonely or isolated, so get out there and find local support groups. Try to stay positive and try to take things one step at a time.



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