

SPOTLIGHT

A chance to get to know the young adults with cancer in your community

For the April 2021 *Spotlight* during Head and Neck Cancer Awareness Month, we could not be more thrilled to feature Nicole Kowalski



Nicole is a 29 year old salivary gland cancer survivor. Diagnosed at 26, she had a maxillectomy in March of 2018 to remove the tumor in her jaw, then underwent 30 days of radiation therapy in May 2018 for a defect in her hard and soft palette. She had a recurrence in December of 2019 and went in for another maxillectomy, at which time the surgeon removed the remainder of her soft and hard palettes along with all of her front teeth with another 30 days of radiation therapy that ended in March of 2020. She has participated in talks about cancer and believes it's important to tell her story at this time of reflection and attention.

AYA@USC: What was the last day before your diagnosis like?

I actually didn't know I had cancer until after my surgery. An early biopsy from another hospital claimed my tumor was benign. So I was shocked when I got the news after surgery. I often think back to the day before my surgery, before everything changed. A close friend drove into town to be with me and took me shopping. We then spent the evening playing Crossy Road (a silly game on Apple TV) and went to bed early. It was gloriously normal."

AYA@USC: What has been the 'Rose' and 'Thorn' of your cancer experience?

Cancer kicked me into high gear. I finally went back to school to finish my Bachelors degree and decided to obtain my Master's in Forensic Psychology, which I am working on now. Having this cancer and conversing with other survivors has made me realize how big of need there is for survivorship therapy among head and neck cancer. A major rose in this whole process is that I have decided that my place as a psychologist will be assisting survivors, patients actively going through treatment, or recently diagnosed of cancer. I want to specialize in seeing patients with head and neck cancer and providing therapy for them. Before my diagnosis, I wasn't sure what I wanted to do with my life. I had so many different directions I could go, but couldn't settle on one. I am grateful I had the opportunity to make a final decision on what I wanted to do with my life.

The thorn of this process has been losing my energy and strength. I was an athlete before all of this happened. I competed in regional and national aerial competitions and was training consistently throughout the week. I'd go to work and train and managed to feel energized the next day. Now, I have a hard time staying awake throughout the day. I get tired so easily and physical activity has become less frequent. If I participate in something intense, like a hike, I'm in bed sleeping the entire next day. I absolutely hate not having energy. There are so many things that I love to do, like baking, hiking, cycling, dancing, aerial work, all of which require some form of energy. I also struggle immensely with trismus or lock jaw. Both radiation sessions and surgeries caused my jaw to tighten and now the largest I can open my mouth is 14mm after stretching. This has affected my speech, my ability to eat almost everything, and my ability to really sing (one of my favorite things to do, I love to perform and act; trismus and loss of energy have severely contributed to my depleted strength).

AYA@USC: What is one thing you wish people knew about cancer?

I want people to know cancer isn't only pink ribbons and rubber bracelets. It's not only chemotherapy. Cancer isn't always a death sentence, but just because it isn't doesn't make it any less scary or painful. It's constant worry about recurrence, even years after being cleared. And while some may not have cancer anymore, it doesn't mean that they're not reminded everyday of their fight. Cancer isn't just donations and charity dinners. There are faces behind the ribbons and the fluff. There are survivors, people who have been through some of the most horrific surgeries and treatments imaginable only to rise above it all. And whether those souls leave us or stay with us, honoring their fight, having compassion for their fear, and understanding they've been through hell will hopefully breed more kindness and love in greater society.



AYA@USC: Are there any quotes or sayings that you have remembered or found helpful?

I tend to hang on closely to the Serenity Prayer. My Aunt Am loved this prayer, she passed from cancer years earlier, but always used this prayer to get her through times of trouble. "God, grant me serenity to accept the things I cannot change, the courage to change the things I can, and the wisdom to know the difference." There's nothing quite like this prayer.

AYA@USC: Do/did you have any animals that have helped you through cancer?

I do! I have my rat terrier Vincent Vega (called Vinny or Mr. Vin) and I adopted Puddin', a mix of chihuahua, corgi, and love, in April of 2018 after my surgery. I wanted Vinny to have a friend and to have additional animals to snuggle with while I went through radiation.



AYA@USC: Was there any art that helped you or that you would recommend? Did you have any musicians/songs that you found yourself listening to? Books that you found yourself reading? Movies/TV shows that you found yourself watching? Comedy, art, theater, etc.

I started reading again and I am in love! I've read over 40 books in the last three years and I am incredibly proud to say that. I've never read so much in my life! I love it. It keeps my mind occupied on a different world, with different characters and different stories. The best book I've read this year has been "That Good Night" by Dr. Sunita Puri. I see Dr. Puri for palliative care and this book is so incredibly moving and beautiful. It really helped me understand what it means to die peacefully and what fighting for your life really means. It's a must read.

AYA@USC: Do you have any 'cancerversary' traditions?

I don't do anything specific, but I try to take time for reflection, mindfulness, and self-love. I like to spend time outside of the city if possible, in the mountains or somewhere quiet where I can be one with the Earth. Recognizing that I fought to be in that spot, feeling the ground underneath me, is incredibly powerful.

AYA@USC: Between need to do, have to do, and want to do- how do you spend your days?

Homework is a priority at the moment. I go to school online, so it is definitely a self-motivated project. I read every night before bed and leave my phone out of the bedroom so there are no distractions. I want to hike more and get more experienced, I would like to start running as well.

AYA@USC: Have you been forced, or chosen to change your life in any meaningful way because of your diagnosis?

Unfortunately, both of my surgeries left me without a hard or soft palette and I have to wear an obturator in order to be able to eat, drink, and speak normally. It is a prosthetic that covers the hole in my mouth and fits into the remaining six teeth I have on the top of my mouth. I suffer from severe trismus and cannot open my mouth wider than 14mm and this changes everything about the way that I eat, drink, and speak. I have to cut food up into tiny pieces and can't bite into anything, like a sandwich or burger. I have permanent numbness inside my mouth on the right side and hearing loss in my right ear. Brushing my teeth is no longer a



quick task. I have difficulty talking to others with my obturator in because there isn't a great seal on it. But because I have trismus, my prosthodontist has to wait until I can open further to make a better one. The chronic pain I've experienced throughout the last three years has caused me to need trigger point injections in my neck and jaw, use pain medication, and have many a sleepless night. Almost everything I do in my daily life has something to do with or will clash with my obturator. Every time I eat or talk or even just mindfully reflect, I feel the plastic in my mouth and suddenly it comes back to be that I've had cancer and that this will forever be my life.

AYA@USC: Is there anything else you would like to add?

Unfortunately, I went through a divorce in 2019, and that was a struggle. Trying to manage my life and health at the same time became overwhelming. But after my split, I met the most incredible man and he is everything I could want in a support system. He is an amazing boyfriend and takes great care of me. Our love for each other has grown throughout this whole process and we've faced things only couples who know each other for a long time face. But we stuck it out and he stuck it out and we celebrated our two year anniversary in March.

I have my pain under control and it doesn't feel nearly as bad as it did two years ago and for that I am incredibly grateful.



If you want to get to know Nicole better, she has an active social media presence. You can find her on Instagram @nicolescrookedsmile, Facebook at Nicole's Crooked Smile, on Twitter @hercrookedsmile, and TikTok @nicolescrookedsmile

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