Expert team helps patient battle tongue cancer

When 56-year-old Gary Nally sought treatment for a cold and a sore throat, he was diagnosed with Stage IVa tongue cancer. “Of course I was terrified, scared,” Nally remembered. A husband and father, Nally works for a coal company in Princeton, Ind.

Looking back, Nally noted his ear had begun to hurt when he ate, but other than that and the sore throat, he had no other symptoms. UK radiation medicine specialist Mahesh Kudrimoti, MD, said most of those diagnosed with this cancer only find it at an advanced stage – many still not experiencing symptoms.

Nationally, one in 324 men and women will be diagnosed with cancer of the tongue during his or her lifetime. In 61 percent of cases, the cancer will have spread beyond the primary site before it is detected. And because the cancer is advanced, patients need to travel to regional medical centers to receive the aggressive treatment regimens required. Nally chose to be treated at UK because it was closest to home.

Like most cancer patients who seek care at the UK Markey Cancer Center, his first stop was to see a surgeon. Nally met with Joseph Valentino, MD, a specialist in head and neck cancer surgery. The year before, Nally had had a stent put in his heart, and as a result, was taking the blood thinner Plavix. Dr. Valentino sent him home to get off of medication for a week prior to surgery. While home, Nally’s throat began to bleed badly and he began spitting up blood.

Nally was rushed to a local hospital. “They didn’t have a clue what to do. They were giving me ice and cold water trying to get this blood to stop and it wouldn’t,” he remembered. “They couldn’t put me on a plane because the weather was so bad, so they put me in an ambulance and took me back to Lexington immediately.” Valentino performed surgery right away to stop the bleeding.

Given the news that he would have to start radiation therapy, Nally and his wife, Penny, got a room in Lexington and met the trio of doctors they would come to depend upon.

“Dr. Valentino was my main doctor, my ear, nose and throat specialist. Dr. Kudrimoti was my radiation doctor, and Dr. Arnold was my chemo doctor. And all three of them were just absolutely excellent.”

— Gary Nally

The three specialists and their teams meet once a week. “Every Tuesday morning they would have a meeting,” he said, “and when it came time for Gary Nally, they would sit around and talk about me – should we do this, should we try this? I felt better knowing it was a team rather than just one person making a decision.”

Nally was hospitalized for a couple of days after the bleeding episode, got out of the hospital and had a PET scan, and then started radiation. His treatment plan called for 35 radiation treatments and three rounds of chemotherapy.

Calling those who go through this special regimen “the bravest of the brave,” Susanne Arnold, MD, views this treatment for tongue cancer as more intensive than what is required to treat many other cancers.
“Other cancer patients undergo chemo and radiation at the same time," said Arnold, "but this is right along the aero-digestive tract and all of your nutrition, all of your speech, all of your airway protection is involved by that organ in the head and neck. And if you’re treating that area, you have to deal with side effects that affect swallowing, nutrition, breathing, speech and all of the bodily functions that happen with your mouth."

“Mr. Nally always came back to clinic saying, ‘I’m ready for more,’” remembered Dr. Arnold, “which was amazing because he had a lot of side effects, but he really wanted to follow the treatment plan. Sometimes we have to say to people, ‘I don’t think you can tolerate the treatment plan. We have to slow down. We have to take a break.’”

When Nally started radiation on Feb. 7, 2011, he weighed 157 pounds. Dr. Kudrimoti suggested he have a feeding tube inserted to ensure he could still get the nutrition and liquids he would need to keep his body strong for the course of the seven-week treatment regimen.

“I refused because my grandmother had one and I remember seeing it and it reminded me of the end of time. So I wasn’t going to do a feeding tube.” Nally’s attitude was consistent with that of most patients — only 20-30 percent agree to a feeding tube up front, Dr. Kudrimoti said.

Nally regrets not taking the advice of doctors, family and friends on this point. By the time radiation treatments were finished on March 30, 2011, he weighed only 134 pounds.

“The doctors had already told me I was not going to make it if I didn’t get the tube put in ... so I went ahead and got the PEG tube. The PEG tube was the smartest thing I ever did. Had I done it to start with, I probably would have healed quicker and faster and better, and I probably wouldn’t have struggled quite as bad.”

Gary and Penny Nally went home on April 4, 2011, and Nally was able to start back to work slowly, working two or three hours at first and then gradually working up to a full work day by August 2011.

“It is a very slow recovery. I thought I could be better faster than this, but it’s just a tremendously slow recovery. I still struggle with my saliva glands, I don’t have them back yet but they’ve gotten better. I’m trying to eat more and put on weight.”

Dr. Valentino took the PEG tube out in January of 2012 once Nally proved he could maintain his weight. “Gary is in the home stretch; he’s doing very well,” said Valentino. “I tell every patient, ‘I pray you have five years of unnecessary office visits with me;’ “ and enjoys being able to say, “You didn’t need to come today, everything’s fine.”

“Usually we don’t like to say a patient has beaten the cancer until we are five years out," said Dr. Arnold. “Gary has a ways to go, but so far things have been very, very good.” Nally will have regular PET scans and follow-up visits to watch for any recurrence.

This isn’t the first time Nally has faced cancer. Almost four years ago he was diagnosed with prostate cancer and sought treatment at another center. “But that hospital is extremely, extremely busy,” said Nally. “UK is extremely busy also, but even though they’re busy, they all made me feel like they had my best interests at heart. When it’s your turn he [Dr. Valentino] gives you as much time as you need.”

Dr. Valentino says he made a conscious decision 12 years ago, “I will take care of the person in front of me,” he told himself, “and do whatever that person needs at that time and the rest of the world will just have to wait. My regular patients all know that if they wait, I’ll be there for them as long as they need me.”

Nally felt the extra attention given by each member of the team. “Every one of them have been superb to me,” he said.

“Patients feel the love we have for them,” Arnold said. “And I’m not afraid to say that’s what it is – love of the patient. Some people think that’s pretty corny. We all do love them, and this is how we show our love and respect for them. We walk the path with them wherever it leads.”

This article was originally published in June 2012.

Update: As of January 2013, Gary remains cancer-free. He continues to credit the expertise and love of his team of doctors with his recovery.

Gary and Penny are planning a trip to Alaska in August 2013.

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– Gary Nally