



Life After Cancer

UPMC's Head and Neck Cancer Survivorship Clinic offers a unique option for patients suffering from the fallout of cancer treatment.

By Shon Meade and Ken Boysen

You've just received a neck cancer diagnosis. Your doctor recommends aggressive radiation treatment to combat the malignant tumor and, ultimately, it will save your life.

The treatment works, but the side effects are devastating. Your teeth may decay or even fall out, and your saliva glands are ravaged, making it nearly impossible to chew and swallow food. Irradiation causes fibrosis of the neck and jaw muscles, making it difficult to turn your head or even open your mouth. These side effects may require their own treatments, like oral surgery, jaw surgery, and physical therapy. In some instances, you may even need to talk to a psychiatrist to manage the anxiety and stress.

"It's a domino effect, it's horrible, and it's why the multi-disciplinary approach of our clinic was necessary," says **Jonas Johnson, MD**, chair, University of Pittsburgh School of Medicine and UPMC Department of Otolaryngology. >

The clinic Dr. Johnson referred to is the UPMC Head and Neck Cancer Survivorship Clinic, a unique clinic formed in late 2016 with financial assistance from The Beckwith Institute, and a group of specialists determined to provide better survivorship outcomes for patients recovering from head and neck cancers.

In the clinic’s view, survivorship starts when cancer is diagnosed. Staff recognize that patients potentially go through physical, social, and economic difficulties during this time and try to help mitigate these issues as best as they can.

“Every treatment leaves people with something. This is nothing new. But with head and neck cancer, it’s your face. It’s what you eat, it’s how you communicate, and how you socialize.”

From Innovative Idea to Reality

Marci Nilsen, PhD, assistant professor, University of Pittsburgh School of Nursing, sits at a table with Dr. Johnson. She was working on a post-doctoral project in early 2016 that observed how patients who couldn’t speak communicated in a hospital. The project involved a systematic review of the long-term side effects of head and neck cancers.

As she and her team poured through over 8,000 case reports, they determined that most outcomes were documented poorly or inconsistently. It was difficult for the team to glean information about who gets these cancers, how often they occur, and preventive measures that may have been taken.

Dr. Johnson regularly saw patients with verbal challenges at his day-to-day practice, so Dr. Nilsen reached out to him, determined to find a better way. “We started really talking about creating a clinic in August of 2016,” Dr. Nilsen remembers. “Dr. Johnson then told me he wanted it up and running by December, and I nearly had a heart attack.”

The two started to think about how the clinic would work, and what their team would look like. They decided the clinic would take a multidisciplinary approach, allowing patients to see multiple specialists — including swallowing therapists, physical therapists, and audiologists — in one place, at one time.

The team approached **Tami Wasserman**, a speech-language pathologist in the Otolaryngology Department, to talk about submitting their idea for a Beckwith Institute Frontline Innovations Grant. After drawing up an outline and submitting their proposal, the grant was approved. “The grant helped a little, but what was even more helpful was having Beckwith lend their name to us,” Dr. Johnson says. “Saying we’ve got the stamp of approval from Beckwith was great.” With the Beckwith grant in hand, Drs. Johnson and Nilsen began their staffing search.

Dr. Johnson convinced a dentist from the Pitt School of Dentistry to visit the clinic once a week. The same happened with UPMC’s Centers for Rehab Services, with a physical therapist, **Susan George**, being ‘loaned’ to provide services to patients at the clinic. They also had additional grant funds that helped pay for a nurse and a swallowing therapist.



Clinicians use a variety of instruments when treating patients at the Head and Neck Cancer Survivorship Clinic.

Before launch, Drs. Johnson and Nilsen knew there would be concerns from patients about how to pay for their treatments. Typically, a patient would have to pay for each service rendered, on top of travel costs to different clinics. But the consolidation of specialties under one roof has kept billing simple for patients since launch. “When patients come to see us, they pay one fee, rather than three, or four, or five,” Dr. Johnson said.

The team understands the realities of health care costs. Some patients simply can’t afford to see so many specialists to meet all their survivorship needs. That’s why the pair tries to help their patients stretch their health care dollars as much as possible. Dr. Johnson refers to the ‘financial toxicity’ of getting sick — if you get really sick and can’t go to work, then you can’t pay your bills. This financial toxicity obviously burdens patients and their families, which is why the clinic has worked to establish relationships with other departments.



Tami Wasserman, left, and Dr. Nilsen explain a scope to a patient.

Having a dentist on the team who specializes in oral pain helped the clinic establish a relationship with the Department of Oral Surgery, enabling it to provide some oral surgery services free of charge. “If a patient tells me that they can’t afford something, we try very hard to figure out a way,” Dr. Nilsen adds. “We work closely with health care providers in some of the hospitals to find ways to lessen the burden.”

A Patient’s Perspective

A lot of people who come to the clinic have had surgery or chemotherapy and radiation — or both. Two years ago, Larry Pollick, a retired English teacher, was diagnosed with throat cancer, impacting one side of his jaw. He underwent a procedure at UPMC Presbyterian to have the tumor removed. However, after a year of being cancer-free, the disease returned and found its way to the other side of his jaw, requiring another surgery.

Larry wasn’t ready to give up his battle with the disease. He said the UPMC team made sure he got the best possible care. Larry’s radiologist and chemotherapist worked diligently to treat him during his second round of treatment at UPMC St. Margaret. His doctors recommended this combination of chemotherapy and radiation to get the best possible result. “The doctors wanted to give the cancer a good fight,” Larry said. “They saved my life.”

Larry was referred to the Survivorship Clinic, and while cancer free, he learned that his jaw was broken due to the aggressive cancer treatment. “Cancer can be confusing.

It overwhelms you, and you just have so many troublesome thoughts,” Larry said in a hushed tone, his voice trembling. “The team at the Survivorship Clinic was able to help me get through a lot of that.”

Looking Toward the Future

The Survivorship Clinic has ambitious goals for the future. Drs. Johnson and Nilsen hope to better understand long-term treatment effects — especially because so many of their patients have received different levels of treatment.

The duo also hopes to train and inspire others to create their own, all-in-one clinics at different hospitals. “If we can put together evidence-based recommendations, then we can get the specialists in Altoona, Erie, Jamestown, and Williamsport to provide the same all-in-one treatment for their patients at home.”

For Larry and the hundreds of other patients the team has seen since launch, the little things go a long way toward ensuring survival and quality of life. “You could tell they were familiar with the nervousness that comes with cancer,” Larry said. “They let you know that you’ll be okay and that they are there to fix people up.” He pauses for a moment before summing up his experiences with the clinic, enunciating each word as clearly as he can. “This clinic is the place that will get you to where you want to be. And it helps that they smile a whole lot.”