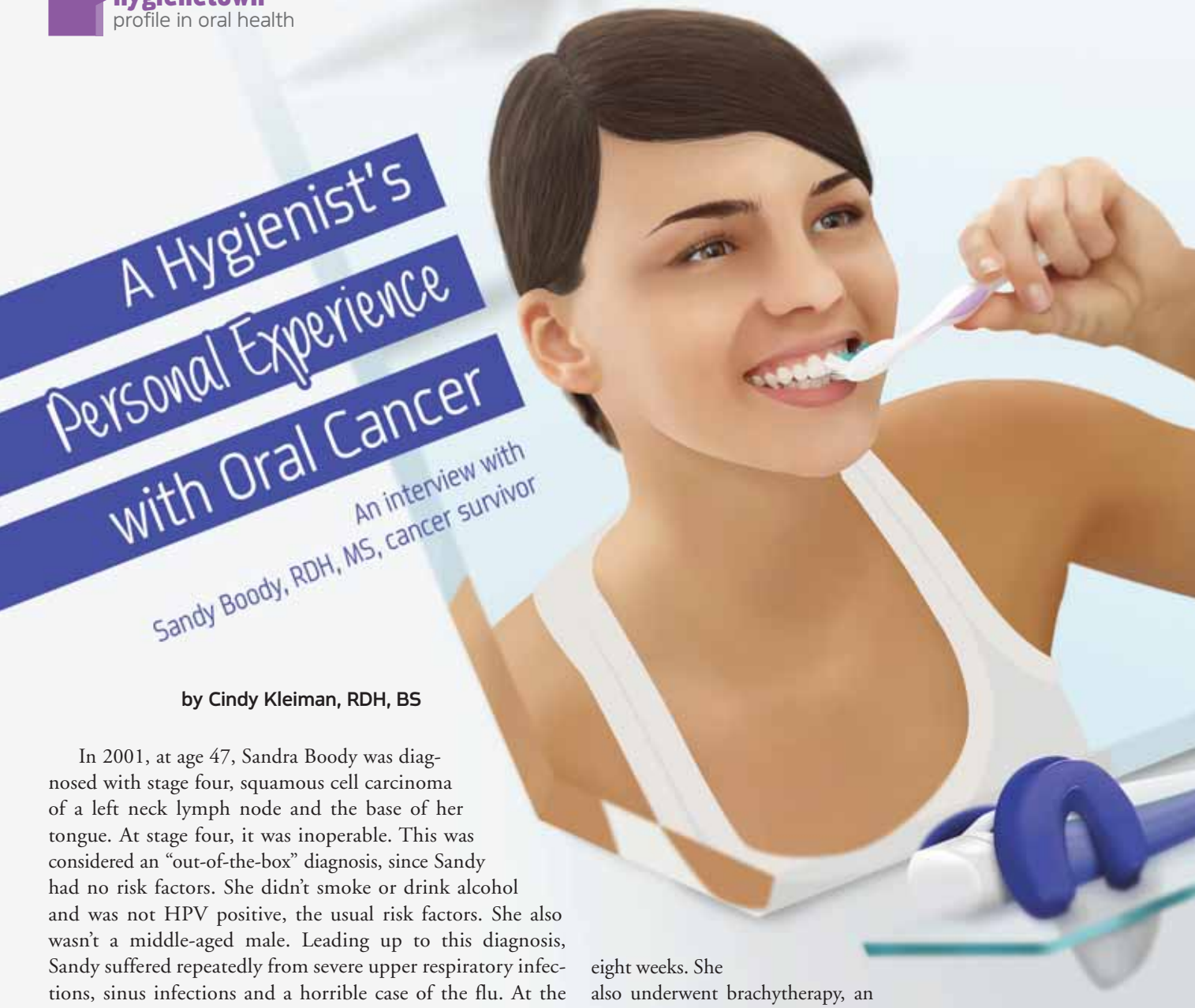
A Hygienist's Personal Experience with Oral Cancer

An interview with Sandy Boody, RDH, MS, cancer survivor



by Cindy Kleiman, RDH, BS

In 2001, at age 47, Sandra Boody was diagnosed with stage four, squamous cell carcinoma of a left neck lymph node and the base of her tongue. At stage four, it was inoperable. This was considered an "out-of-the-box" diagnosis, since Sandy had no risk factors. She didn't smoke or drink alcohol and was not HPV positive, the usual risk factors. She also wasn't a middle-aged male. Leading up to this diagnosis, Sandy suffered repeatedly from severe upper respiratory infections, sinus infections and a horrible case of the flu. At the time, multiple lymph nodes were swollen on both sides of her neck and some ulceration of the tissue at the base of the tongue was noted by the ear, nose and throat (ENT) specialist. Actually, she saw several ENTs as her health never returned to normal. Sandy's request for a needle biopsy of the swollen lymph node on the left side of her neck, which had not returned to normal, was denied by more than one ENT. She didn't fit the usual profile for cancer, so why bother doing the biopsy. Eighteen months later, after multiple rounds of antibiotic therapy, sinus radiographs that showed nothing, and constant, extreme fatigue, Sandy proactively referred herself to the Head and Neck Cancer Center at the University of Pittsburgh. The department head at the Head and Neck Cancer Center performed a surgical biopsy and delivered the devastating diagnosis.

Treatment included daily external beam radiation therapy with concurrent weekly chemotherapy for a treatment time of eight weeks. She also underwent brachytherapy, an internal, sealed source radiotherapy plus surgically inserted catheters into the tumor and lymph nodes. The combination of these treatments all contributed to severe xerostomia. The treatment protocol was an extreme attempt to save her life. As terrible as the treatment was, Sandy is thankful that it worked and that she has been cancer free for 11 years.

Xerostomia is the most common, interruptive side effect of cancer treatment. Because normal as well as cancerous cells are destroyed, the side effects range from acute to long lasting. In some cases the xerostomia is so severe, patients have to stop cancer therapy due to this painful side effect. Sandy has suffered with severe xerostomia since undergoing therapy. Her daily oral hygiene routine has changed over the years, as new products are brought to market. Her personal experience provides dental team members with insights to help them care for patients before, during and after cancer treatment. We interviewed Sandy to determine the differences between oral hygiene care then and now.

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Sandy, thank you for taking time today to answer questions about your personal experience with oral cancer. Being a dental hygiene educator, when you were diagnosed did you think you already knew what oral care protocol would work for you?

Sandy: When I was diagnosed, the most common recommendation was custom fluoride trays. Back then, most dental professionals were just making fluoride trays and giving out samples of dry-mouth products. This is what I was teaching because it was the standard of care back then. When diagnosed, I made the trays for myself immediately and fully expected to use them for fluoride applications. I was surprised to find that the fluoride gel application was difficult to tolerate. The taste was unbearable and the viscosity of the gel caused gagging. Fluoride gel is very uncomfortable on inflamed, xerostomic tissues.

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Now, I teach the making of custom oncology trays to deliver oral moisturizing gels and remineralizing products, not fluoride gels. Fluoride varnishes have replaced tray delivery of fluoride. One of the new uses for the trays when worn overnight is to protect sensitive mucosa. I was surprised to learn that my own teeth became weapons of mass destruction against my dry, sensitive mucosa. Sharp edges and cusp tips can easily tear and cut mucosa inside the cheeks and lips; especially sharp are the cuspids and premolars. The oncology trays provide mucosal protection from dangerously sharp tooth surfaces.

What was your oral care routine when you began this journey?

Sandy: A decade ago, I used the fluoride trays and used over-the-counter dry-mouth toothpaste, dry-mouth oral rinse and dry-mouth gels. I also rinsed with sodium bicarbonate and used various moisturizing lip balms. Nothing was really helpful back then. Things have changed a lot in just the past few years.

What is your oral care protocol today?

Sandy: Today, my oral care protocol focuses on elevating my oral pH and protecting both my soft tissues and teeth. I use a small-headed, soft-bristle toothbrush. Several brands advertise them as "sensitive" toothbrushes. I do prefer a power sonic toothbrush on a low setting. I use an SLS-free toothpaste and extra fine dental floss. For a rinse, I use a prescription brand called NeutraSal Rinse, a super saturated calcium phosphate rinse. I use this rinse morning, evening and after meals.

During the day I chew xylitol-sweetened gum. At the moment, MightyFlow Green Tea moisturizing gum is my favorite. Prior to lecturing and throughout the day I use MedActive Oral Relief Spray.

In the evening I brush with a prescription-level fluoride paste, rinse with NeutraSal and wear the oncology trays filled with MI Paste Plus. I also use Spry Nasal Spray and MedActive Oral Relief Spray on my tongue.

For daily comfort, I have to carry products with me wherever I go. I really thought I'd find one line of products to take care of all the dry-mouth and demineralizing problems, but instead it's a lifetime of using multiple products to get through the day. And my personal protocol changes as new products are introduced.

What are your recommendations for dental teams faced with patients undergoing cancer treatment?

Sandy: Here are my top ten general recommendations for treating patients prior to, during and after cancer treatment:

1. Conduct a comprehensive dental exam using a CAMBRA assessment tool.
2. Evaluate the dentition and remove rough surfaces and sharp cusps to reduce potential tissue trauma.
3. Advise patients wearing full and partial dentures that they are at risk of tissue trauma and candida albicans infections.
4. Provide detailed self-care instructions using specific, simple aids, including the use of over-the-counter products, (e.g., explain how to apply gel to the teeth, tissues and tongue).
5. Replace and restore faulty restorations before cancer treatment and place sealants to prevent caries and enamel washout, also any needed periodontal therapy.
6. Create printed instructions including websites providing information on oral health care and in-depth oral hygiene instructions. Include instruction for a daily self-check for soft-tissue lesions, sore spots and inflammation that should be reported to the oncologists.
7. Minimize enamel and dentin breakdown with monthly fluoride varnish applications and sealant applications.
8. Tell them to strive for five xylitol exposures each day, using xylitol-sweetened gums, lozenges, pastes, rinses and sprays in their daily routines. Also have them check the pH of oral care products they use, including rinses.

9. Address the fact that altered taste sensations make it hard to chew and swallow food by recommending neutralizing rinses, sprays and gels that coat and moisturize the oral tissues.
10. Advise patients to avoid foods that are spicy, crunchy and sugar-laden, and consult an oncology nutritionist for a list of foods to avoid.

You lecture to dental professionals all over the country. What do your audiences take immediately back to their practices?

Sandy: My full-day courses are packed with information, but the two changes most likely to be implemented when attendees return to their offices are using a written protocol and fluoride varnish applications. I hear back from those who attend my lectures that they actually write up a protocol, print it out and give it to patients. They also schedule their patients undergoing cancer treatment for monthly fluoride varnish applications. These applications begin before treatment, and continue through and after cancer treatment.

Any last advice for clinicians?

Sandy: We are entering a new era in dentistry and oncology with new products supported by research. The medical community is beginning to embrace the oral-systemic connection. They are now looking to us to help them navigate the difficult course of treatment for patients with teeth, implants and restorations. The educated consumer is proactive and interested in preserving their dentition and their dental investment. A very exciting future is ahead! ■

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Bios

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Sandra Boody is a graduate of the University of Pittsburgh with experience in clinical practice including dental, hospital and nursing homes, education, curriculum development, corporate sales and myofunctional therapy. She also speaks on a variety of topics relating to the oral health of those undergoing cancer therapy. Sandra can be reached at sandraboody@gmail.com.