

# Intimacy and Cancer

*Providing patients and caregivers with information and counseling about sexual wellness keeps partnerships strong during cancer treatment and beyond.*

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**When Vonda Zimmerman, 49, of Tulsa, Oklahoma, was diagnosed with squamous cell cancer of the anus in December 2012, she thought she had a clear understanding of what to expect from her treatment regimen.**

She underwent chemotherapy and 20 rounds of radiation over three months and, as she anticipated, experienced side effects that included fatigue and skin irritation. Vonda's treatment was successful, and she has had no evidence of disease since she completed treatment in May 2013.

But while Vonda's treatment was effective and went according to plan, she was surprised by one significant side effect: She did not expect her experience to affect intimacy.

Vonda, who has been married for 23 years, experienced vaginal dryness and tissue shrinkage from the radiation she received to her pelvic area, which made intercourse painful. Radiation also caused Vonda to enter early menopause—complete with its hot flashes, mood swings, decreased libido and vaginal dryness—making the side effects even worse.

Pelvic radiation also caused muscle spasms, which resulted in muscle pain. Vonda tried physical therapy and chiropractic care to address pain in her lower back and right hip, but after almost two years the exercises offered little relief. "I struggled with the slow progress," she says.

As she continued to experience discomfort and saw the impact on her intimate

relationship with her husband, Vonda searched for answers about changes in intimacy following treatment but found little information.

### **Addressing an Unmet Need**

Vonda's challenges with side effects related to sexuality and intimacy are not unique. Many patients and their partners struggle with the physical and emotional impact of treatment on their intimacy. Unfortunately, for too long these needs have not been addressed, leaving patients to struggle in silence.

"As health care providers, we have historically done a poor job of educating patients about the impact that cancer and treatments for cancer can have on their overall sexuality," says Traci Owen, RN, BSN, Survivorship Care Manager at Cancer Treatment Centers of America® (CTCA) in Tulsa, Oklahoma.

Now, with data revealing the significant impact of this side effect of treatment among patients—48 percent of CTCA® patients surveyed reported distress related to sexual interest and function—Owen is working to help patients and their partners navigate this aspect of survivorship. "Conversations with our patients and existing survey data told us we had an opportunity to improve the holistic care that we strive for every day," she says.

In response, Owen has developed a sexual wellness program at CTCA in Tulsa to help patients and their partners. The program addresses the issue comprehensively, utilizing a wide range of clinicians; the team includes physicians, nurses, pharmacists, mind-body therapists, a dietitian, the radiation care manager and an education nurse specialist.

"If we can keep partners strong and connected to one another, then our patients will always do better," Owen says of the motivation she feels to help patients with this program.

### **How a Cancer Diagnosis Can Affect Intimacy and Sex**

When one partner in a couple is diagnosed with cancer, a role reversal can occur as caregiving duties shift and couples are challenged in new ways. "Partners or spouses take on medical tasks that they likely are not prepared for, such as managing medications, performing complex dressing changes following surgery, managing drains and tubes and post-operative care," says Owen. "It shifts the dynamic for couples."

In addition to these practical considerations related to caregiving that may change a couple's standard operating procedure, patients can experience mood changes and grapple with emotional distress related to their changed physical appearance. Whether it is hair loss, weight loss or gain, surgical removal of a body part or scarring—all have an impact on a patient's sense of self and confidence: "Body image plays a large role in our willingness to be vulnerable and intimate with our partner," says Owen.

Side effects of cancer treatment that affect both men and women, including fatigue, nausea and vomiting, can also put a damper on desire. Men can experience erectile dysfunction and urinary or bowel incontinence during or after treatment. "Sexuality and virility is a huge part of male identity," says Owen. "They can become intimidated, have performance anxiety and start pulling away from their partner. It is hard for them to talk

about it. And then their partner thinks they are the problem.”

Side effects unique to women that may affect intimacy include symptoms related to early menopause—as Vonda experienced—like hot flashes, vaginal dryness and lowered libido, for those who have had their uterus and ovaries removed as part of treatment. Most cannot manage these side effects with hormone replacement therapy because it can put them at higher risk for additional cancers.

These side effects of treatment are often accompanied by financial issues and ongoing physical changes stemming from surgery, chemotherapy or radiation that can result in long-term challenges for a couple long after they have left the hospital.

Owen says the medical profession can do a better job of preparing cancer patients and their partners for these challenges by letting them know why changes are happening to their body and how to address them. “Just by acknowledging clinically what is happening can be so freeing for many couples.”

### **Redefining Intimacy and Finding Solutions**

When a partner undergoes cancer treatment, couples can benefit from understanding the distinction between sex and intimacy and redefining their ideas of intimacy. “Intimacy is the big-picture relationship between partners—the handholding, the patting, the smiles, the inside jokes—all the touch and trust building that happens within a healthy relationship,” says Owen. In contrast, the act of sex is part of the expression of intimacy.

You can have sex without intimacy and vice versa, she says. “Most people are seeking a real, emotionally deep relationship with another person, whether or not that includes intercourse.”

Owen says helping patients find ways to maintain intimacy during and after cancer treatment can help couples overcome the challenges they may face as a result of physical changes that affect their sexual relationship.

For instance, women often experience lowered libido during treatment, which can challenge couples’ ability to connect. Helping women engage emotionally in the idea of being intimate can help build a connection, Owen says: “We do not have a magic pill, but we can focus our thought process. We tell people to return to a dating mentality. You can prepare emotionally for an encounter, make dates with each other and think about what you are going to wear and how you want to look.”

Physically, to counteract the vaginal dryness and tightness women may experience, Owen has patients begin a vaginal hydration program that includes the use of vitamin E, coconut oil and over-the-counter lubricants and creams. Pelvic radiation can also narrow vaginal tissues, in which case vaginal dilators are recommended to restore vaginal capacity and elasticity.

Men who have had surgery or radiation for prostate cancer often need penile rehabilitation. Experts at the sexual wellness center work with male patients to recommend appropriate options to increase blood flow in the penis to help stimulate and

maintain an erection. Options include medication, implanted penis pumps, constriction loops, testosterone replacement and penile injections.

"We always take into consideration where a patient is in their life cycle," says Owen of all medical and mind-body interventions. "We take their medical history into account and help patients find out what feels good in their new body at each stage of life. We help patients set realistic goals and find a routine that works for them." Ultimately, she says, every couple has to determine the approach that works best for them.

### **A New Perspective Can Lead to Increased Intimacy**

For Vonda and her husband, as for many couples who have faced a diagnosis, intimacy after cancer has meant redefining their original notions of what an intimate relationship looks like. Vonda worked with Owen to help revise the traditional view of intimacy she and her husband had and to create a new dynamic definition that suits their life now: They enjoy couples massages and take short trips together, enjoying the time to connect. "There are other things besides sex that allow you to feel close," Vonda says. "It is even better now because we are more engaged with our minds. It gives us conversation time."

For Owen, helping couples open up about these issues and providing education and resources is deeply rewarding: "A good 85 percent of my meetings with patients and couples involve some tears—stemming from the relief they feel just to be talking about it and knowing they don't have to suffer silently," she says. "When you can help a couple reconnect and understand one another's perspective, powerful healing can take place."