

NAVIGATING SEXUAL INTIMACY WITH AN OSTOMY

(FOR UROSTOMY, ILEOSTOMY, COLOSTOMY, AND TRACHEOSTOMY)

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Note: This handout is offered as a communication aid for patients and their providers. It is not a substitute for professional examination, diagnosis, or treatment.

INTRODUCTION

Sexual intimacy is an essential aspect of life. Having an ostomy and a cancer diagnosis may make the prospect of engaging in intimacy daunting. There are several paths to help make sexual intimacy less intimidating.

LOVE YOURSELF AND YOUR BODY

Self-love and affirmation are helpful steps toward sexual intimacy with an ostomy. Create frequent private time, even a few minutes in the shower, to practice loving yourself, your body, and your battle scars. Thank your lungs for breathing air and your mind for working; thank your skin for sensation. With intention, think about things you like about yourself – such as your laugh, your enjoyment of history, or birdwatching. Speak out loud to yourself about how you have overcome the adversity of your cancer and your treatment. These are forms of practicing self-affirmation, which is effective in dealing with adversity in a healthy way.

Trace over your body with a washcloth or soft piece of fabric and enjoy the sensation. Remind yourself of your strength and vitality in being a survivor.

HOW TO MAKE AN OSTOMY MORE DISCRETE

There are many ways to make an ostomy covert for intimate moments:

Ostomy Appliances and Pouch Strategies

- Empty an abdominal ostomy (such as a urostomy, ileostomy, or colostomy) bag before engaging in touching your intimate partner. Ensure the appliance is secure and well-sealed to avoid accidental disconnection or leaks.
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- Smaller, close-ended, low-profile pouches are available for sexual intimacy, sometimes called *passion* pouches.
- Cloth pouches are available to cover the ostomy bag and hide the contents.
- Consider odor-absorbing tablets or drops for a colostomy or ileostomy bag.

- Change the urostomy pouch, as urine breaks down the plastic, causing an odor.
- <u>Clear tracheostomy secretions</u> before engaging in intimacy.

Ostomy Intimate Wear

Various forms of intimate wear of ostomy are designed to secure the ostomy bag to prevent shifting during physical activity and cover the bag and/or stoma.

- There are online resources for intimate ostomy wear for males and females, people of all sizes and body shapes.
- A cummerbund, teddy, or high-waisted crotchless panties work well to cover an ostomy.
- Covering an ostomy may boost confidence and decrease a sense of self-consciousness.

Food and Beverage Awareness

Practice <u>awareness of foods and beverages</u> that may cause gassiness and or produce more pungent smells in stool or urine or help reduce odor.

Urostomies

- Drinking cranberry juice can control urine odor. Staying hydrated with water keeps urine more diluted and the smell of urine breaking down the plastic.
- Some foods can cause an odor in urine, such as asparagus.

Colostomies and Ileostomies

- <u>Several foods</u> often lead to ostomy odor and or gas, such as beans, fish, spicy foods, garlic, onion, cabbage, broccoli, and eggs. See what foods create more odor for your ostomy.
- Some vitamins can also cause unpleasant smells.

TALK OPENLY AND HONESTLY

Having cancer and an ostomy are challenging subjects to broach with an intimate partner or romantic inter.

Consider writing down talking points about how you want to share your cancer diagnosis and ostomy. Maybe <u>practice with a friend</u> or family member and ask for their feedback. The United Ostomy Association of America (UOAA) suggests <u>things to talk about</u>:

- PHYSICAL LIMITATIONS (VAGINA DRYNESS, PROBLEMS WITH ERECTIONS)
- PAIN, IF PRESENT
- FEARS (OF BEING UNLOVABLE, NAKED, LEAKAGE, ODOR, REJECTION)
- MUTUAL EXPECTATIONS
- WHAT SEXUAL ACTIVITIES ARE ENJOYED BY EITHER PARTNER
- WHAT SEXUAL ACTIVITIES ARE NOT ENJOYED
- ANGER, RESENTMENT, GUILT, OR OTHER EMOTIONS THAT INTERFERE WITH THE DESIRE TO SHARE SEX

UOAA explains that intimate partners (or potential intimate partners) of an Ostomate may fear causing harm or pain with sexual intimacy. UOAA cautions not to <u>mistake this fear for rejection</u>.

Talk and listen openly with each other, without judgment.

APPROACH INTIMACY SLOWLY

Start with small steps. Kissing and hugging are intimate contact.

Consider trying Sensate Focus, which is a technique of progressive, warm intimacy exercises without judgment. Sensate Focus successfully establishes intimacy when there is self-consciousness and altered body image. After Cancer has a patient education handout, Cornell University has an excellent online guide to <u>Sensate Focus</u>.

Physical Positions

For people with a tracheostomy, choose a position for intimacy that protects and secures the tube.

Abdominal stomas typically do not have nerves to signal pain if the chosen sexual position causes friction. Stomas have a lot of blood vessels and may bleed with trauma. Side-lying intimate positions can avoid trauma.

Inability to Achieve or Maintain an Erection or Ejaculate

Avoid panic if there is an inability to have or keep an erection or ejaculate. These inabilities may be related to surgical healing, nervousness, or anxiety. It may take up to two years after surgery to determine if erectile dysfunction is more permanent. The nerves controlling erection and ejaculation, which run near the rectum, can be damaged during surgery for colorectal cancer.

There is help for erectile dysfunction with several possible interventions. Consider pelvic floor therapy, a vacuum erection device, and talk with a urologist about other possible interventions. It is possible to orgasm without ejaculation.

See the After Cancer Handout on Penile Rehabilitation with a VED

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Rediscover Intimacy

Sensate Focus is a technique for progressive intimacy that may help resolve erectile dysfunction related to anxiety or body image. Sensate Focus can also help intimate partners practice warm, engaging intimacy without an erection.

Other forms of intimacy and touching can be satisfying and rewarding to you and your partner. Intimate and alternative means can accomplish penetration, such as dildos and sex toys. Other ways of being intimately touched can induce pleasure in place of an erection or ejaculation. The exploration of alternatives can be endless and beautifully intimate.

See the After Cancer Handout on Sensate Focus: Rediscovering Intimacy with Touch

Don't Penetrate the Stoma With Anything

The stoma is not a sexual organ. Do not penetrate the stoma under any circumstances with anything.

SEXUAL INTIMACY IS POSSIBLE, CAN BE WONDERFUL, AND LIFE-AFFIRMING AFTER CANCER AND AN OSTOMY

The United Ostomy Association of America (UOAA) has a <u>comprehensive guide for intimacy</u> with an ostomy. UOAA's website, <u>ostomy.org</u>, shares personal stories of thriving with an ostomy, tips and tricks for dealing with ostomies, and available support groups for ostomates.

To further your knowledge and comfort, After Cancer recommends also reading the following patient handouts:

Managing Sexual Dysfunction with Pelvic Floor Physical Therapy Let's Slide Into Lubricant Sensate Focus: Touching Exercise to Rediscover Intimacy Practical Solutions for Low Libido

Works Cited

American Cancer Society. "Intimacy and Sexuality When You Have an Ostomy." American Cancer Society, 2 Oct.

2019, https://www.cancer.org/cancer/managing-cancer/treatment-types/surgery/ostomies/stomas-or-ostomies/sex.html.

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Colorectal Cancer Alliance. "Sexual Health - Ostomy." *Colorectal Cancer Alliance*, https://www.ccalliance.org/colorectal-cancer-information/health-and-wellness/ostomy/sexual-health.

Accessed 22 Aug. 2023.

- Mayo Clinic Staff. "Ostomy: Adapting to Life after Colostomy, Ileostomy or Urostomy." *Mayo Clinic*, 28 July 2022, https://www.mayoclinic.org/diseases-conditions/colon-cancer/in-depth/ostomy/art-20045825.
- Md, David Hanscom. "Affirmations and Neuroplasticity." *Psychology Today*, 30 Jan. 2020, https://www.psychologytoday.com/us/blog/anxiety-another-name-pain/202001/affirmations-and-neuroplasticity.
- United Ostomy Association of America. *Intimacy after Ostomy Surgery Guide*. https://www.ostomy.org/wp-content/uploads/2018/03/Intimacy-After-Ostomy-Surgery-Guide.pdf. Accessed 22 Aug. 2023.
- Health, C. (n.d.). *Sensate focus*. Retrieved August 21, 2023, from https://health.cornell.edu/sites/health/files/pdf-library/sensate-focus.pdf