Intimacy after Ostomy Surgery

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1 Sex and Stomas: Myths and Truths

Despite our differences and regardless of race, creed, or culture, every person on this planet has one thing in common. We are sexual beings — whether we are young or old, male or female, gay, straight, or fluid, single or married, any age or background, or whether we have a stoma. Not only can sex continue to be or actually begin to be fun and pleasurable, but it’s important to our overall emotional and physical sense of feeling okay. Sexuality makes us feel whole and normal, desirable and loveable.

What can happen, however, is that everything associated with an ostomy can prevent people with an ostomy (as well as their sexual partners) from relaxing and enjoying the experience of sex. This can create added anxiety in the bedroom.

Ostomy surgery may alter your sexual functioning but it won’t take away or destroy your sexuality.

Many sexual problems experienced after ostomy surgery may be more emotional than physical and are often based on misinformation. Here are a few:

<table>
<thead>
<tr>
<th>Myth</th>
<th>Truth</th>
</tr>
</thead>
<tbody>
<tr>
<td>And they lived happily ever after.</td>
<td>This is a fairy tale. Relationships are like tides; sometimes they’re up and sometimes they’re down. Adjustments can be made to keep the joy of sex alive, but sex alone doesn’t make a relationship secure.</td>
</tr>
<tr>
<td>Intercourse is the only way to be intimate with a person.</td>
<td>Regardless of your sexual orientation or gender identity, giving and receiving pleasure can be expressed in many ways—hugging, kissing, cuddling, holding hands, masturbation, oral sex, stimulation with the hands, and even sleeping in the same bed.</td>
</tr>
<tr>
<td>My partner should know what pleases me. I shouldn’t have to explain it.</td>
<td>Unless your partner has extrasensory perception (ESP), they can’t read your mind. Tell your partner what you like, what you don’t like.</td>
</tr>
<tr>
<td>You can’t get pregnant with a stoma.</td>
<td>People with stomas can and do get pregnant and have healthy babies. It is important, however, to be followed by healthcare professionals throughout the pregnancy.</td>
</tr>
</tbody>
</table>
No one will ever love me because I have a stoma.

It’s reasonable to feel this way. People who’ve lost a breast to cancer or lost a limb feel this way too. Your attitude and how you treat yourself sets the tone on how others treat you. If you feel comfortable and accepting of your new body, your partner is likely to do the same.

I’ll never have an erection again.

If there’s no erection the first time you try after surgery, don’t convince yourself this is the way it’s going to be. Rest. Relax. Regain your strength and try again. If the problem persists, talk to your doctor.

You must ejaculate to have an orgasm.

It is possible to have an orgasm without ejaculating (a dry orgasm).

Having sex will spread my cancer to my partner.

Cancer isn’t spread through sexual contact. However, ‘safe sex’ should be used to prevent sexually transmitted infections.

The odor from my stoma will be a turn-off for my partner.

Deodorizers especially designed for use with an ostomy are available to help reduce odors from stool and urine. Some are used in the pouch and some are taken by mouth. Modern pouches are made of odor free materials. To remain fresh, keep your body and pouching system clean.

Body movements and pressure of our bodies during sex will hurt my stoma.

Close body contact and movement during sex won’t hurt your stoma. However, nothing (fingers, objects) should be put into the stoma. A stoma is not a sexual organ.

Older people don’t have sex.

Ha! Many seniors, including ones with an ostomy, are sexually active.

Be sure to seek credible sources of information: your doctor, your WOC Nurse (Wound Ostomy Continence Nurse) or OMS (Ostomy Management Specialist), UOAA, and other recognized authorities on the Internet.
Human Sexuality

*Sex isn't so much as what happens between your legs....
Sex is more about what happens between your ears.*

When you're healthy, your desire for sex holds a certain level of importance because your other needs are fulfilled. When illness or medical treatments interrupt your life, sex may not be so important to you. As you begin to return to a normal lifestyle, your need to regain feelings of sexuality; sexual intimacy become more important.

Linked closely to our feelings of sexuality, however, is how we think about ourselves and our bodies - our body image. It's how we see ourselves in the mirror and how we think our body works, looks, smells and appears to others. That's why, when something as dramatic as ostomy surgery changes our body image, our feelings of sexuality and self-esteem sometime feel threatened, even though we're still the same person (and often healthier) than we were before the operation. Let's face it, even without an ostomy, developing a satisfactory sex life isn't always easy.

Everyone, regardless of whether they have an ostomy or not, experiences sexual difficulties at some time during their life. These issues may be emotional or physical, but often can be both. Unfortunately, many individuals don't discuss this with their partner, let alone with medical professionals or their friends. However, after ostomy surgery there can some physical and emotional changes that can have a direct impact on sexual functioning. There may be even a component of pelvic pain that is preventing you from being intimate with a partner. These changes can cause you to feel alone with your concerns. The best way to understand how these changes after ostomy surgery might affect your ability and desire to participate sexually, it is important to first understand how our cycle of sexual response worked before surgery.

## 2 HOW OUR BODIES WORK DURING SEX

Sexual response consists of three phases:
- sexual desire
- sexual arousal
- orgasm

The phases of response are the same whether you are stimulated by a partner or by yourself. Various hormones and two different sets of nerves control the way our bodies respond during sexual activity. One set of nerves controls the "between the ears" part of sex by allowing us to feel these emotions, sensations and changes. The other set controls "the between the legs" part -- our body's ability to actually have the physical changes by controlling the flow of blood and activating the muscles in our sex organs or genitals.
Sexual desire is exactly what it says — the yearning and wanting to have sex — (being turned on, excited or horny) — the restless feeling or emotional tickle we get. This desire to enter into sexual activity can be triggered (or blocked) by many things: our senses, (sight and smell, for example) and emotions (our thoughts and fantasies), but also our hormones (the male hormone testosterone and the female hormone estrogen). Testosterone is produced in the testicles and estrogen is produced in the ovaries. Adequate levels of these hormones are needed for sexual functioning.

After you feel desire, your body enters into the second phase, called sexual arousal. You feel excited, passionate, and stimulated. Your heart rate and breathing speed up. Muscles in the body and sex organs become tense. Blood rushes to sensitive areas on your skin and sex organs. Men experience an erection of the penis and women’s vaginas expand and get moist. Each person’s level of sexual desire and arousal varies. Some people do not experience this at all. It is not uncommon for our levels to change over time and under certain circumstances.

Orgasm is also a complicated physical and sensory experience made up of pleasant sensations and muscle contractions in the sex organs. Clinically speaking, an orgasm is simply the sudden release of pooled blood in the sex organs and tension in the muscles — much as sneezing releases the pent-up pressure you feel before you sneeze. You could say that an orgasm is a "sneeze" in the sex organs!

No two people experience orgasm the same way. The "sex between the ears" nerves control the pleasant sensation felt during orgasm. During orgasm, muscle contractions in men propel semen through the opening in the penis, and women experience rhythmic muscle contractions in the vagina. The "sex between the legs" nerves control this part of orgasm.
Intimacy after Ostomy Surgery

Is it my body? Or is it my head?

Although ostomy surgery and the diseases and conditions that caused you to have the operation may leave you temporarily weak or with a reduced sex drive (the medical term for sex drive is libido, pronounced la-bead-oh), having an ostomy doesn't mean you have to ignore your sexuality. How we feel affects what we are able to do. After surgery, it's often hard to get back into feeling "sexy" again. Indeed, you might not have any sexual feelings for days, weeks, or even months. But don't worry, this is normal.

How can you think about sex if you're still in pain or physically exhausted? Let your body recover and learn to manage your stoma before tackling intimacies in the bedroom.

Some people start thinking about sex immediately after surgery. They may have been unable to participate sexually due to weakness or illness for quite a long time before surgery and are raring to go afterwards. Once again, these folks sometimes are disappointed the first time they attempt to have sex because their bodies haven't had enough time to recover.

The first time you become intimate after surgery things may not go perfectly. Some people may have trouble getting and keeping an erection and others may have pain during intercourse. This may feel upsetting and you may begin to question yourself and if your surgery caused these problems. You may also worry and have fears about your ability to perform. You may be worried that the stoma or pouching system will offend your partner. You may be worried about leakage, the pouch falling off or about odor. You may feel depressed or unattractive. Examine your medications as you may be taking a drug that may interfere with your sexual response. It also may be that your physical stamina may have not be completely restored.

Take some time to sort through your feelings and decide if they stem from your surgery and illness or past sexual experiences. It is important to be honest with yourself and take time to discuss your feelings with your partner. Learning to navigate and understand sex and sexuality after an ostomy can be confusing. You are encouraged to seek professional help from a counselor, your physician or a sex therapist.
Common Reactions to Ostomy Surgery
That May Interfere with the Ability to Share Sex

- Embarrassment
- Shame
- Fear of pain, leakage, rejection, being naked
- Anger
- Depression

Physical Changes Caused by Ostomy Surgery
Because ostomy surgery takes place in the pelvis and part or all of some organs are removed, it makes sense that sexual functioning could be affected. However, the changes that can occur in men are quite different than those that can occur in women. Also, the type of ostomy operation you've had (ileostomy, colostomy, urostomy) and the reason you've had it (for example: cancer of the rectum versus Crohn's Disease) play a role in what physical changes have been made and the specific affect it will have on your sexual response.

For example, a man who's had an abdominoperineal resection for cancer of the rectum may have difficulty getting or keeping an erection after surgery. Because the man had cancer, the surgeon had to remove a bigger portion of tissue around the rectum to prevent the possible spread of the cancer to healthy tissues. This removal of a wider piece of tissue often damages the nerves and blood vessels that control the ability to have an erection. This condition is called impotence or erectile dysfunction (ED). On the other hand, a man who has had his rectum removed for ulcerative colitis or Crohn's Disease may not have trouble with erections after surgery because his disease didn't require a wide removal of tissue around the rectum. Therefore, the nerves and blood vessels to the penis were not damaged.

Prior to any type of ostomy surgery, it is important to have a discussion with your doctor, WOC nurse or OMS concerning the possibility of changes in your sexual functioning.
### 3 Common Sexual Problems after Ostomy Surgery

<table>
<thead>
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<td>Seldom</td>
</tr>
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<td>Seldom</td>
</tr>
<tr>
<td>Pelvic exenteration (removal of bladder, rectum, ovaries, uterus, colon and sometimes all or part of the vagina)</td>
<td>Sometimes</td>
</tr>
</tbody>
</table>
Common Sexual Problems Related to Chemotherapy and Radiation

- Pregnancy is not recommended during chemotherapy.
- Chemotherapy and radiation may reduce the ovaries’ capacity to produce ripe eggs.
  - People undergoing chemotherapy, radiation therapy or removal of the ovaries may want to preserve healthy eggs prior to surgery and these treatments if future parenthood is planned or desired.
- These therapies may damage sperm cell production.
- Vaginal dryness may occur.
- You may want to preserve healthy sperm prior to chemotherapy, removal of the rectum for cancer, or radiation therapy if future parenthood is planned or desired.

4 Talking with Your Sexual Partner

One of the most important things you can do to strengthen your intimate relationship is to talk to your sexual partner.

It will be difficult to have sexual intimacy without exposing your stoma/pouch. It is probably not the best time to teach your partner about an ostomy during a passionate encounter.

We now have communication systems that allow someone on earth to talk to someone in space or on the moon, but we often cannot talk to the ones we love about what we feel, what is in our heart, and what we want and need.

Most people are unfamiliar with ostomy surgery and what a stoma looks like and how it functions. Most people will not know how it may have changed your sexual function. If you meet someone or are already in a relationship with someone with whom you desire a sexual relationship, you will need to decide how and when you want to share this with your partner.

Research has indicated that partners of people with an ostomy worry about communication issues too. A lack of correct information can increase these worries and inhibit sex, so it’s to your advantage to teach your partner. If your partner is worried about hurting the stoma, don’t misinterpret this as a rejection. An intimate relationship is one in which it matters how well you can communicate about two of the most personal of human functions — body elimination and sex. Your partner will take the cue from you. Be mindful that the feelings of your partner are real and shouldn’t be denied any more than your own.
Things to Talk About

- Physical limitations (vagina dryness, problems with erections)
- Pain, if present
- Fears (of being unlovable, naked, leakage, odor, rejection)
- Your mutual expectations
- What sexual activities you like to do
- What sexual activities you do not like to do
- Anger, resentment, guilt or other emotions that interfere with the desire to share sex

The more you can share information, the less difficult it will be to share your body. For example, if you are worried about painful intercourse after surgery, you may prefer manual stimulation to orgasm by your partner. This can relieve a lot of tension and frustration at the same time it serves as a "bridge" to the time you are ready for intercourse. However, your partner won't know this unless you talk about it.

Since your attitude is probably the most important ingredient for a happy sex life, you should do whatever you feel you need to do to feel relaxed, free, and at ease with your body. Talking about these issues is a giant step forward.
5 THE EFFECT OF MEDICINES ON SEX

Americans take a lot of medicine. Seniors take more medicine than younger people and women take more than men. In fact, the average older person takes 4.5 prescription medicines and 2.1 non-prescription medications (such as, vitamins, over-the-counter cold medicine and other drugs, herbals, supplements).

If you’ve had ostomy surgery, have a chronic illness or are receiving treatments for other conditions you’ll likely be taking one or more medications. If your surgery was fairly recent, your body still hasn't fully recovered from the effects of anesthesia and you may still be taking some pain medicine.

Sometimes combining prescription and non-prescription medicines together can cause some unexpected side effects in the place you least expect it — the bedroom.

The following is a list of some common types of medications that can interfere with sexual desire, erection, and sexual functioning. It's a good idea to discuss your medications with your doctor or pharmacist to check for any sex-related side effects. For example, a person might be taking an antidepressant after surgery to help cope with their emotional reaction to surgery. Problems with an erection may be only a temporary one caused by the antidepressant rather than the operation.

Common Sexual Side Effects of Medicines
- Reduced desire
- Difficulty with ejaculation
- Difficulty getting and/or keeping an erection
- Decrease in the strength of orgasm

Some Medications That May Affect Sexual Functioning
- High blood pressure medicine
- Antidepressants
- Pan medicine
- Alcohol
- Tranquilizers
- Antihistamines
- Sleeping pills
6 PREPARATION FOR THE BEDROOM

Most people do certain things to get ready for sex, things that make them feel good such as showering, shaving, applying after shave or perfume or wearing sexy lingerie. For some, preparation for intimacy may be setting a romantic mood with soft lights, champagne, a candlelit dinner or romantic music. People with an ostomy sometimes feel that they need to do a little more. The following are a few tips that may help you feel more comfortable in the bedroom.

- Always practice SAFE SEX (foams, lubricated condoms, other forms of contraception)
- Focus on your feelings, not the pouch.
- Empty the pouch before engaging in sexual activity.
- Make sure the pouch is secure; reinforce it with paper tape around the edges.
- If you wear an ostomy pouch belt, make sure it's clean.
- Make sure you are clean — better yet, jump in the tub or shower together.
- If you’re concerned about the appearance of the pouch use a pouch cover or a pouch you can't see through.
- Use a “passion pouch” during sex. These are smaller, closed-end, disposable pouches that are shorter and less bulky than standard drainable pouches. There are many brands available.
- The “side-lying” position may work better on the stoma side because the pouch will fall away and not come between you and your partner.
- If you have a colostomy and you irrigate, irrigating just before you have sex might allow you to wear a small patch or "security pouch" during that time.
- There are also many items available specially designed for ostomy coverage and intimacy that may be purchased online.
7. **CONTROLLING GAS AND ODOR**

**Gas**
- Many over-the-counter medications, such as Mylanta Gas® (Johnson & Johnson — Merck Consumer Pharmaceuticals Co., Ft. Washington, Pa.) and Phazyme® (Glaxo SmithKline, Philadelphia, Pa.), are effective in reducing gas.
- Dietary supplements, such as Beano® (Glaxo SmithKline, Philadelphia, Pa.), are also quite effective in reducing gas related to the breakdown of complex sugars in gas-causing foods and are available as tablets or drops.
- Avoid "gassy" foods such as cabbage, sodas, beer, beans, and chili if you know you’re going to be sexually active.
- If you have an ileostomy or a colostomy, gas filters are available in both drainable and closed-end pouches. These help to keep the pouch flat and deodorize gas.

**Odor**
- If you have a urostomy, avoid foods that cause strong odor in the urine, such as asparagus.
- Specially formulated deodorizers can be put directly into the pouch. NOTE: Never use an aspirin tablet in your pouch as a deodorizer. Aspirin can irritate the stoma.
- If you have an ileostomy or a colostomy, gas filters are available in both drainable and closed-end pouches. These help to keep the pouch flat and deodorize gas.
- Use a room freshener after emptying your pouch (example: Ozium Air Sanitizer® (Atmosphere Products Co., Inc.)
- Always check with your WOCN or physician before taking anything by mouth.

8 **HELPFUL HINTS**

8.1 **Hints for Women**
- Use personal lubricants for vaginal dryness (for example Astroglide®, K-Y Jelly): you can buy these in most grocery or drug stores.
- Hormone creams or vaginal suppositories are sometimes prescribed for vaginal dryness. Talk to your doctor about them.
- Consider wearing crotch-less panties, "teddies," or a short slip or nightie, or something with a snap- or cut-out crotch.
- If the pouch or other stoma covering seems to be in the way or causes pain during intercourse, experiment with different positions.
- You might not come to orgasm the first time you have sex after surgery. Don't worry, this is normal.
8.2 Hints for Men

- In the “man on top” position, lean a little toward the pouch-free side of your tummy.
- Consider wearing a cummerbund around your midsection to prevent the pouch from flapping.
- Try wearing some attractive boxer shorts if you’re concerned about exposing the pouch.
- Continued problems, such as the inability to get or maintain an erection should be discussed with appropriate health care professionals. There are solutions to almost every sexual problem, so don’t panic!

8.3 LGBTQ+ Concerns

Ostomy surgery affects people of all sexual orientations and gender identities. Removal of the rectum and closing of the anus may present a challenge for some with an ileostomy or colostomy, so other methods of sexual pleasuring need to be discussed and researched. The LGBTQ+ community has the same concerns and fears about sex after ostomy surgery as anyone else. An LGBTQ+ ostomate can have fulfilling and satisfying relationships once communication is open and candid with their medical team and partner. The GLO (Gay Lesbian Ostomate) network is available for support and there is a special breakout session at UOAA’s National Conference.

8.4 Spinal Cord Injury, Sex and Ostomy

It is common for people who have spinal cord injuries to have a stoma — sometimes two stomas. Ostomy surgery restores control over the bladder and rectum that was lost when the spine was injured. These individuals may be wheelchair or bed bound, so sexual activity has additional limitations not experienced in other people. Spinal cord injured or wheelchair bound people should discuss their ability to participate in sex as well as alternative methods of giving and receiving sexual pleasure.

8.5 “Sex and the Witty”

It’s true that ostomy surgery and sex are serious “business.” But perhaps that’s all the more reason to keep and develop a sense of humor about it. Joy, humor and laughter are wonderful, easily available, low-cost tools for bringing comfort into a relationship.

"Laughter is the shortest distance between two people"

Victor Borge

An ostomy should not be viewed as the end to living, but simply living with a new end in view!

Embarrassing situations are often eased by a quick sense of humor. Untimely noises from a stoma can be a straight line for many funny comebacks. Come on, isn’t "bathroom humor" the kind of humor that makes everyone laugh? Take advantage of it.
8.6 Birth Control for Men and Women

Women
Birth control methods should be discussed before and after ostomy surgery if this is of concern to you. A woman with an ostomy who uses birth control pills needs to remember that this drug is usually absorbed in the small intestine. Therefore, if you have a urostomy, sigmoid or transverse colostomy, you should have no trouble absorbing birth control pills. However, there is a slight chance the pills may not be absorbed if you have an ileostomy — leaving you at risk of becoming pregnant. The use of diaphragms and IUDs (intrauterine devices) should also be discussed with healthcare professionals, especially in women who have had their rectums or part of the vaginal wall removed. Today, there are many options for women besides birth control pills: hormone skin patches, regular injections, etc. Discuss these issues with your doctor, gynecologist, or Ostomy Nurse, and pharmacist.

Men
If your surgeon feels there is a chance you may become sterile after your ostomy surgery and you still want to be able to father a child, you may want to think about storing your sperm before your surgery. Discuss these options with your surgeon or other health professional.

8.7 When You Should get Professional Help

Problems with sex that last for several weeks or months shouldn’t be ignored. You’re not alone. There are many options available to you in solving them, whether the solutions involve sex therapy, couples therapy, talking to someone from a support group, surgical corrections, or the use of medical devices and medication. Ask for help if you have any of the following problems that don’t go away:

- Pain during intercourse that lasts for weeks and months after surgery
- Difficulty making sexual adjustments for you, your partner, or both of you
- Inability to talk about sex with your partner

8.8 Help for Impotence

Millions of men and their partners suffer with impotence. There are many reasons for it — physical changes, diseases such as diabetes and alcoholism, the aging process, or emotional difficulties, such as fear, stress, worry, anger, or frustration. Sometimes these physical and emotional problems can happen at the same time.

For example, a slight physical problem with erections can get worse because the man is worrying about it all the time. The cause of the impotence will decide what the treatment should be. Hormone treatment, medications, drug injections into the penis, counseling, and penile prostheses (a surgically implanted device that enables a man to have an erection) are all possible treatment options. Talk with your doctor or Ostomy Nurse. Don't worry in silence.
9 RESOURCES AVAILABLE

9.1 United Ostomy Associations of America (UOAA)
UOAA is a volunteer-managed non-profit organization whose vision is the creation of a society where people with bowel and urinary diversions are universally accepted socially, in the workplace, medically and psychologically. UOAA has a comprehensive website, www.ostomy.org, that includes ostomy information, support group locations and discussion boards so people can connect, ask questions and share advice. Call UOAA at 800-826-0826 to find the affiliated support group in your area.

The official publication of UOAA, The Phoenix magazine, is America’s leading source for ostomy information, education and inspiration. Subscriptions to the magazine are a source of funding for UOAA and are available by calling (800) 750-9311 or going online: www.phoenixuoaa.org.

9.2 Health Care Professionals
- Colorectal surgeons
- WOC, OMS or Ostomy Nurses
- Urologists
- Gynecologists
- Urogynecologists
- Psychiatrists
- Psychologists
- Sex Educators, Counselors, and Therapists
- Fertility specialist
- UOAA trained ostomy visitors

9.3 Helpful Websites
- American Association of Sexuality Educators, Counselors, and Therapists
  - www.aasect.org
  - will help you find a professional near you
- National Institutes of Health, National Institute on Aging
  - www.nia.nih.gov
  - click on "Health Information" for Sexuality in Later Life brochure
- Wound, Ostomy and Continence Nurses Society
  - www.wocn.org
  - will help locate a certified WOC Nurse near you
- American Cancer Society
  - www.cancer.org
- Crohn's and Colitis Foundation of America
  - www.ccfa.org
10 GLOSSARY OF TERMS

**Body image:** the way a person views how his or her body looks, smells and appears to others.

**Erectile dysfunction:** also called E.D. See *impotence*.

**Erection:** a penis that is hard or rigid enough for sexual activity.

**Ejaculation:** release of sperm from the penis, or fluid from or near the vagina.

**Gender Fluid:** When gender identity shifts between masculine and feminine.

**Hormones:** substances formed in certain glands in the body that enter the bloodstream and affect or control the activity of some organs. The so-called "sex hormones" are estrogen, the female hormone and testosterone, the male hormone. Adequate levels of sex hormones are needed for optimal sexual functioning.

**Impotence:** the inability to have an erection that is firm enough or lasts long enough for successful intercourse. Also called erectile dysfunction, or ED. Impotence is not the same thing as being sterile.

**Libido:** the urge or desire to have sex.

**Masturbation:** self-stimulation of the sexual organs.

**Orgasm:** the "climax" of intercourse or masturbation. A total body response at the height of sexual excitement. The sudden release of pooled blood in the sex organs and tension in the muscle.

**Sterility:** *Male sterility* is a lack of sperm or enough healthy sperm that makes it possible to make a woman pregnant. *Female sterility* means the absence of a uterus to carry a child, or the inability to become pregnant.