

Lifestyle Series

Love and Sex for People
with an Ostomy



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Please note that this booklet is a supplement to and not a replacement for the advice from your healthcare professional.

Love and Sex

If you have a stoma or are expecting to have ostomy surgery, you are probably wondering how the most intimate parts of your life will be affected.

This booklet is about how love and sex fit into the lifestyles of men and women who have stomas. Here you will find advice about sex and related matters that can help you return to a lifestyle that suits you and your partner: A lifestyle in which sex plays an appropriate part. If you have a partner, encourage him or her to read it along with you.

This information can help you both find positive ways to adapt to the changes caused by a stoma. We want to provide answers and suggestions that benefit you, and that means being clear and direct - addressing concerns that are typically not part of common conversation. Because of that, you will find parts of this pamphlet are sexually explicit.

A glossary at the end of this booklet briefly explains terms which may not be familiar.

Feeling Concern is Natural and Normal

When facing the prospect of stoma surgery or when lying in a hospital bed looking at the pouch, there is a good chance a person will feel lonely and worried.

What if my friends and partner look at me differently, maybe even reject me in some way? How will sexual activity work if I am wearing a pouch? Will I be able to have children? Questions and concerns like this are natural and normal.

Your answers to these questions depend on a number of things: the nature of your illness, the type of operation you have had, your age, your gender, your attitude and also the nature of the type of relationships you have already had during the course of your lifetime.

Good news. Many people have happy and fulfilled lives and relationships after their operations. It is possible to have an improved sex life after surgery, and many people go on and have children and families.

To put the whole thing into perspective, there is no such thing as one specific type of sex life that is right for everyone. Sex is unique to each person and to each individual relationship and lifestyle. Because sex occurs within relationships, the kind of sex life you have will reflect the nature of your relationship. After surgery, you will need to find a way of living with your partner that suits you both.

Just about everyone, even people who have never been ill, never had surgery and certainly don't have a stoma, experience sexual difficulties and problems at some point in their life. Do not assume that people who experience sexual difficulties following surgery do so because of surgery. They may have experienced difficulties and problems before surgery, even if the stoma becomes a focal point for the problems. Because of this, this booklet focuses on relationships as much as on the physical side of sex.

Of course, there are numerous physical reasons why people may experience sex problems after their operation, and these are discussed in this booklet.



Your Relationships and Self-Confidence

When you are fully clothed, no one needs to know that you have an ileostomy, colostomy or urostomy. Your surgery and stoma can be a secret and does not need to be revealed to anyone else - anyone else, that is, until you are ready to take your clothes off and engage in sex! Without clothes, the pouch can hardly be ignored.

If you have a partner of long standing, he or she will have shared your illness and surgery with you. The pouch will not be a surprise, but when you first get into bed together after surgery, even if you don't intend to have sex, you will need to recognize its presence. For a couple in an ongoing and loving, caring relationship, the novelty of the pouch soon wears off and it can be largely ignored.

But what if you have a new partner who is unaware of your surgery? Many people wonder how to best handle this situation.

If a relationship is becoming serious, it is worth discussing your situation before the relationship gets physical. If you whisper this tenderly in your partner's ear in a moment of passion, this one surprise can make the situation awkward!

Plan ahead by rehearsing a short explanation to yourself. It might be easiest to start with the fact that you had a serious illness which had to be treated surgically. The result is that you wear a pouch. Once you have decided how to talk about your situation, it will be easier to find a comfortable time to explain to a potential new partner that you wear a pouch.

Of course, it is possible that a sexual relationship occurs soon after you meet someone, before you have time to get to know someone well enough to discuss such matters. This raises your risk level by surprising your partner, as well as the risks everyone faces with casual sex.

It is always possible that a prospective partner might not want to continue the relationship when he or she learns about the stoma. This is the kind of experience no one wants. If it happens, remind yourself that people without stomas are rejected for all kinds of reasons. In fact, if a potential partner loses interest, it may not be because of your stoma. And, if your stoma is a serious barrier in a relationship, there is a strong possibility that the relationship would not have worked anyway.

Even with surgery, you always have a choice in your relationships. This includes sexual relationships with long standing partners or new partners and in non-sexual relationships with friends, relatives and colleagues at work.

If you think of yourself only in terms of your stoma, you convey the message that the only thing that matters is your stoma. If you do this, there is a good chance other people will respond by not treating you as a whole person.

On the other hand, you can present yourself as someone who was ill and now has a stoma which is a part, but not the only part, of your life. There are other aspects of you that are much more important than your stoma - your job, your family, your wit, your charm, and your interest in other people.

If you show that your stoma is not important in terms of the way you want to live your life, then that is what will most likely occur. Others will take their cue from you.



You and Your Partner

If you are in a long standing relationship, your partner should be involved at the earliest opportunity - that is, when you learn that you need surgery. He or she may be concerned about the sexual part of your relationship. Make arrangements for your partner to talk to the surgeon and the Stoma Care Nurse when you are not present, so it is easy for questions to be asked. This can provide much needed reassurance.

As the person who shares your life and cares for you, your partner needs to be included. Many couples say that sharing this experience brings them closer together.

Many people say it helps to have their partner involved early on, when the pouch is changed in hospital. Your partner can see the stoma, thus reducing concerns. They can learn along with you when a healthcare professional is there to answer questions you both may have. For many people, the reality of a stoma is much less of a shock than the anticipation.

Recovery from a major operation takes time. People having stoma surgery very likely have been debilitated before surgery, and this slows the recovery process. Do not expect to resume sexual relationships as soon as you get home from hospital.

There is no set time when to resume sexual relationships after surgery. A rule of thumb: if a person can walk half a mile unaided and without becoming breathless or being in pain, it is probably all right to resume full sexual relations. It's a good idea to discuss with your surgeon when you can resume sexual activity. Once you start sexual relations, this is the time to be gentle.

Before resuming full intercourse, some people try masturbation or ask their partner to do this for them. This helps build confidence, is pleasurable and reduces fears about whether sexual feelings are possible. If the idea of masturbation is morally wrong or unappealing, don't do it, but many couples find it a good place to begin.

The first few times you have sex, make sure your pouch is secure. Always empty your pouch before you begin to make love. Never try to make love when it is full or half-full.

Having Sex

How do people with stomas have sex? The answer is exactly the same way as people without stomas. Conventional positions are almost always possible for those who want to have sexual intercourse. It is a matter of taste and what you are comfortable with.



Remember that being loving, kissing and touching are an important part of sexuality. You will need to take it gently, and the tenderness and friendliness that are part of the pleasure of sex is the best way to begin.

People with stomas worry about whether their pouch will impede easy movement and get in the way. If the pouch is emptied before intercourse, it can be folded up and secured with some tape.

Use a nice cotton cover during sexual activity; this will prevent the pouch from rubbing on your and your partner's skin. If you usually wear a transparent pouch, the cover hides the contents. You can also use a pouch with an all cloth option. There are also smaller pouches or "caps" which are discreet and can be worn just for these special occasions.

Contraception

Many people with stomas become happy parents. Conception is wonderful, if that is what a couple wants.

However, if you have a stoma, are sexually active and do not want to have children, you will need to prevent pregnancy by using contraception or a form of family planning.

Any of the common methods are possible - a condom, a barrier (the cap, intrauterine device), the pill or an injection. Men may have vasectomies as a permanent means of family planning.

There is some evidence that the contraceptive effect of the birth control pill is limited for people with ileostomies. It is thought that the medication passes through the digestive system very quickly without being absorbed into the body, and the protection of the pill is lost. Talk to your doctor or your family planning clinic about this.

If the person with a stoma is infertile already, either from a disease or because they have had a vasectomy or have been sterilized, then clearly there is no need for contraception.



Issues for Men

The most common and in many ways the most difficult challenge for men is impotence following surgery. This is the inability to get or sustain an erection long enough to ejaculate or climax.

Lack of completion in the sex act can cause tension for a couple. Even if the woman does not feel sexually frustrated, she may come to believe that her lover no longer finds her attractive, and that is why he does not make love to her. Communication between the partners is key to helping couples stay close and maintain understanding. Gentleness, tenderness and being relaxed, as well as having a positive self-image, are essential to a happy and enjoyable sex life.

Temporary impotence is not unusual following stoma surgery, so don't think that all is lost if, within a couple of months after surgery, you have not begun to have sexual relations. The healing process sometimes takes a long time. It can take up to two years before it is clear whether a person is permanently impotent or whether sexual function will come back.

Impotence is a highly complex phenomenon. It can occur in men of any age and for many reasons which are not a direct result of surgery. It certainly is a problem that is not limited to people with stomas.

Impotence can be caused by psychological and physical factors. Sometimes it occurs because the man believes or comes to believe that he is unable have an erection or come to climax. This can become a vicious cycle of failure, loss of belief and continued failure.

Issues for Men *(Cont'd.)*

Lifestyle can play a part in both causing and contributing to impotence. This may have little to do with surgery. Lifestyle issues include:

- making love when tired
- using drugs and/or alcohol
- smoking
- too much concern and worry about performance

It's possible that simple changes in lifestyle can help. If these remedies don't assist, it is worth seeking a medical opinion.

The causes of impotence can be physical. For men, there is a risk that the nerves governing erection and ejaculation can be damaged in surgery. Erection happens when stimuli travel along the nerve pathways. These fibers run close to the rectum. If these fibers are damaged in surgery, the ability to have an erection can be wholly or partially lost.

Ejaculation is also dependent on the nervous system. These pathways are vulnerable in surgery too. Impotence can be more common for men with a colostomy than an ileostomy because colostomy surgery may cause damage to the tissues and the nerve pathways responsible for erection and ejaculation. Surgery for bowel cancer is extensive and, therefore, can be more damaging.

According to available data, age seems to be an important factor. Older men have more problems. This may happen because their interest in sex is diminished or because older men are more likely to have a colostomy than ileostomy (bowel cancer is more common in older age groups) or some mixture of these factors. It is far from clear.

In the case of permanent impotence, there are possibilities for help. Over the past few years, medical science has developed surgical techniques that help some impotent men, including people with stomas. This type of surgery is highly specialized. If you are interested, the first step is to talk to your Stoma Care Nurse, surgeon or family doctor.



Issues for Women

Besides concerns about having sex, women with stomas may be thinking about having children. A normal birth with vaginal delivery is not only feasible, it is quite common as long as a woman's reproductive organs are undamaged and working normally. Having a stoma should have no effect, although the pre-existing disease might create problems.

As far as the mechanics of sexual intercourse are concerned, there are several types of problems which a woman with a stoma might encounter. The first relates to the perineal wound that is incurred when the rectum is removed during lower bowel or rectal surgery. This wound can remain tender for a considerable time following surgery, and sexual intercourse can be painful.

A second problem is that the space left when the colon is removed sometimes allows the uterus to shift backwards. This can cause pain during intercourse. Third, some women with stomas find there is a decrease in feeling and sensitivity of the clitoris. This may be due to nerve pathways to the clitoris becoming impaired by surgery.

Another frequent problem is vaginal dryness, making intercourse difficult and uncomfortable. Finally, penetration may be painful and uncomfortable simply because of the scarring of the tissues following removal of the colon or bladder.

Not every woman has the same type of surgery, and many of these problems are related to specific types and extent of surgery.

There are solutions. For dryness, a lubricating jelly can be used. If your partner wears a lubricated condom, this may help. It is also possible to have surgical reconstruction of the perineal wound, particularly if sinuses or blind tracts are present.

If penetration is painful, there are alternate sexual positions to try. If the rectum has been removed, the missionary position (the female lying on her back with her partner on top of her) may be uncomfortable. One option is for the man to enter the vagina from behind, the female kneeling with her knees apart while the man kneels behind her. Another way is for the woman to sit astride her partner while he lies on his back, and she guides his penis into her vagina.



Homosexuality

For gay men and women, having a stoma is not in itself any more or less of a problem than for heterosexuals.

However, if a gay man has used his rectum as a receptive orifice during intercourse, there can be a problem if the rectum is removed in surgery. Removal of the rectum and anus depends on the surgical procedure, the type and extent of the disease and the potential risk to the life of the patient.

The decision to remove the rectum is a matter of clinical judgment. Therefore, it is important for a gay man to discuss the issue with the surgeon before the surgery. That way, they can jointly explore the possibility of keeping the rectum in place and assess the risks that might arise from doing so.

One important word of warning: the stoma must never be used as a point of entry for sex. To do this, is to risk damage to the stoma and will almost inevitably result in more surgery.

Final Thoughts

This booklet provides an overview of sexual problems and difficulties encountered by people with stomas, and it gives suggestions on addressing these problems. Of course, it can't answer every question. If you are looking for more detailed information on one of the topics, you may find it through your Stoma Nurse or doctor, or there are additional booklets that might be helpful.

Not only that, but given the personal nature of sex, the variations are almost infinite. If you want to return to the active sex life that you enjoyed before surgery or perhaps even better (if only slightly different), chances are that you can and will. Having a stoma does not mean you have to stop enjoying this natural physical side to your life.

If your sex life is not the same as before surgery, it can be upsetting and frustrating. Being unable to have sex is not an ultimate disaster, even though it might seem that way at times. Many people live very happily without it by choice.

One piece of advice applies to everyone: Keep the sexual side of your life in perspective. You are a person with all sorts of traits and characteristics, of talents and interests, with friends and relatives. Sex can be fun, sex can be great, but it is only one part of you.

Additional Information: Please visit the Hollister website www.hollister.com or C3Life.com

Glossary

Clitoris

A highly sensitive region of the female - located above the entrance of the vagina. Frequently responsible for orgasm

Conception

The moment when a woman becomes pregnant

Condom

A male contraceptive device which fits over the penis

Contraception

A method used to prevent pregnancy

Contraceptive

A device or drug used to prevent pregnancy

Colostomy

A stoma opening into the large bowel

Diaphragm/ Cap

A female contraceptive device

Ileostomy

A stoma opening into the small bowel

Intra-Uterine Device (IUD)

A contraceptive device planted directly into the uterus (womb) to prevent pregnancy

Intercourse

Sexual activity between one or more partners

Masturbation

Pleasure of one's own or another's sex organs usually to orgasm outside of intercourse

Ostomy/Stoma Association

An association or club for people with stomas

Orgasm

Also known as climax or coming

Perineum

The area between the anus and the vaginal area

Pouch

A specialized bag used to collect bodily wastes from the stoma

Rectum

The last portion of the digestive tract before the anus. Stores stool prior to a bowel movement.

Sterilization

A procedure to prevent conception

Stoma

An artificial opening into the body. From the Greek word meaning mouth or opening. Also known as an 'ostomy'

Stoma Care Nurse

Also known as SCN, or ET (Enterostomal Therapy Nurse), STN (Stomal Therapy Nurse), WOCN/WOC (Wound Ostomy & Continence Nurse). This is a specially trained nurse with broad expertise for the care of people with stomas.

Urostomy

A urinary stoma. Also known as urinary diversion and often (ileal) conduit

Uterus

Also known as the womb. Where the baby grows before it is born.

Vagina

The passage leading from the uterus to the vulva in females

Vasectomy

Male sterilization to prevent sperm coming through the penis into the vagina.

Vulva

The external organs of the female, including the labia, clitoris and opening to the vagina