



Living with an Ostomy:

Sex & Parenthood



Ostomy Care
Healthy skin. Positive outcomes.



If you have a stoma or are expecting to have ostomy surgery, you are probably wondering how intimacy and/or planning for a family will be affected.

This booklet is about how sexual relationships might fit into the lifestyles of people who have stomas. Here you will find recommendations and related matters that can help you return to a lifestyle that suits you and your partner.



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A glossary is included at the back of this booklet to help with some terms with which you may not be familiar.

You might also be wondering how a stoma affects pregnancy and childbirth. Besides giving general recommendations on keeping healthy during pregnancy, we cover special problems that may occur during pregnancy and childbirth when you have a stoma.



Feeling Concerned

Is Natural and Normal

When facing the prospect of stoma surgery it is normal to have questions and concerns.

What if my friends and partner look at me differently, maybe even reject me in some way? How will sexual activity be impacted if I am wearing a pouch? Will I be able to have children?

The good news is many people have happy and fulfilled lives and relationships after their operation. It is possible to have a normal sex life after surgery, and many people go on to have children and families.

Your relationships and self-confidence

When you are fully clothed, no one needs to know that you have an ileostomy, colostomy or urostomy. You can decide if you want to share information about your surgery or not. However, if you are planning to be intimate and remove your clothes the pouch can't be ignored.

A partner of long standing will have shared your illness and surgery with you. The newness of the pouch will soon wear 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 type of situation.

If a relationship is becoming serious, it is worth discussing your situation before the relationship gets physical. Plan ahead by rehearsing a short explanation to yourself. 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 practice how to talk about your situation, it will be easier to find a comfortable time to explain it to a potential new partner.



You and

Your Partner

If you are in a committed relationship, involve your partner as soon as you learn that you need surgery. They may be concerned about the sexual part of your relationship. It may help to make arrangements for your partner to talk to the surgeon and the Stomal Therapy Nurse (STN). Many couples say that sharing this experience brings them closer together.

Part of involving your partner early on is having them see the pouch changed in the hospital. The simple act of seeing the stoma helps minimise concerns. Seeing the pouch change procedure while a healthcare professional is there to answer questions is beneficial for you both. 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 may 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 the hospital.

TIP

There is no set time when to return to sexual relationships after surgery. Talk to your healthcare professional about when you can resume sexual activity.





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 preference and comfort level.

When you and your partner are ready, take it slowly and gently to start. Just remember that loving, kissing and touching are an important part of sexuality, and tenderness and friendliness are part of the pleasure of sex as well.

If you are undergoing further treatment such as chemotherapy or radiation therapy, this also can affect sexual desires, ability to have sexual intercourse, pregnancy and/or conception itself.

Pouch and attire

People with stomas may worry about whether their pouch will impede easy movement and get in the way. You may want to empty your pouch before intercourse.

If the pouch is not covered with fabric, some people choose to use a cotton cover that is specially made for ostomy pouches during sexual activity; this will prevent the pouch from rubbing on you and your partner's skin. If you usually wear a transparent pouch, the cover hides the contents. Some people choose to wear a garment such as a silky or cotton vest-like top that actually covers the pouch and their torso. There are also smaller pouches which can be worn discreetly for certain stomas.

Mechanics and penetration

As far as the mechanics of sexual intercourse are concerned, there are several types of situations someone 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 amount of time following surgery, and sexual intercourse can be painful.

A second situation is that the space left when the colon is removed sometimes allows the uterus to shift, which can cause pain during intercourse. Third, some people 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.

Sometimes the rectum, or a portion of it, is removed in surgery. This situation may have an impact if the rectum has been used for penetration during intercourse. If surgery has involved removal of part of the rectum, this should be completely healed before any attempt to use it for penetration is considered. 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 to discuss the issue with the surgeon before the surgery. That way, they can explore with you the possibility of keeping the rectum in place and assess the risks that might arise from doing so.

FACT

The stoma itself has no nerve endings and cannot feel. It should never be used for intercourse.

Impotence

For some, impotence following surgery can be an issue. This is the inability to get or sustain an erection long enough to ejaculate or climax.

Temporary impotence is not unusual following stoma surgery, so don't think that all hope 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. If you are undergoing further treatment, such as chemotherapy or radiation therapy, this also can affect your sexual desires and ability to have sexual intercourse.

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 fibres run close to the rectum. If these fibres 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. Surgery for bowel cancer is extensive and therefore, can be more damaging.

Impotence is a highly complex phenomenon. It can occur in people of any age and for many reasons, which are not a direct result of surgery.



In the case of permanent impotence, there are possibilities for help. Over the past few years, medical science has developed surgical techniques that may help some people, including people with stomas. This type of surgery is highly specialised. If you are interested, the first step is to talk to your STN, surgeon or healthcare professional.

Vaginal dryness

Another common issue is vaginal dryness, making intercourse difficult and uncomfortable. Penetration may be uncomfortable because of tissue scarring following removal of the colon or bladder.

Not every person 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.

It is important to remember that dryness may be a side effect of a medication you are taking, and your healthcare professional will be able to provide recommendations.

If penetration is painful, consider trying alternate sexual positions.

TIP

Referral to a physical therapist may also be a helpful option. A physical therapist can teach exercises that strengthen the pelvic floor, which is important for satisfying intercourse.

Contraception

Many people with stomas decide to become parents. However, if you have a stoma, are sexually active, and do not want to have children, you may want to prevent pregnancy by using contraception or a form of family planning.

Any of the common methods are possible — including a condom, a barrier (the cap, intrauterine device), the pill, or an injection. Some people 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 healthcare professional or your family planning clinic about this.

Unless you know that you or your partner are infertile, or one of you has been sterilised, if you are sexually active and do not want to get pregnant, it is always recommended to use a contraceptive. Most methods of contraception are just as effective for people with stomas as without stomas. However, family planning for those with stomas may require a little more thought.

Some types of stoma surgery may alter the anatomy of the vagina and uterus. Because of this, diaphragms or caps may not always be a suitable means of contraception, as insertion and retention may be difficult. This is the same for the intrauterine device (IUD) or coil. Discuss this with your healthcare professional to find out if there have been any surgical changes that could prevent you from using these devices.

The oral contraceptive pill may not be suitable for some people with ileostomies, depending on how much small bowel remains. A dosage adjustment may be necessary if absorption in the small bowel is not very good. In some individuals with ileostomies, absorption can be unreliable so the oral contraceptive pill may be unsuitable. It would be wise to discuss this further with both your doctor and your pharmacist. Another more suitable form of hormonal contraception may be required. Hormonal injections, such as progesterone, or a birth control patch are options to consider. Again discuss this with your healthcare professional.

Condoms are an effective alternative for those who have difficulty utilising other contraception methods. They are highly reliable, provided they are used consistently.



Conceiving a Child

In addition to concerns about having sex, people with stomas may be thinking about having children. A normal vaginal delivery is quite common as long as the reproductive organs are undamaged and working normally. Having a stoma should have no effect, although the pre-existing disease might cause difficulties.

A stoma should not make the difference in your ability to conceive and bear a child. If you do experience difficulties in getting pregnant, the reasons are most likely no different from those encountered by those who do not have a stoma.

Before attempting to become pregnant, check with your healthcare professional regarding your health status. You may be asked to visit a gynaecologist for pre-pregnancy counselling to discuss any possible difficulties. Once your healthcare professional says you are fit enough to attempt conception, there is no reason to wait.

Early prenatal care is important. If you think you are pregnant, it is essential to tell your healthcare professional. Like others who are pregnant, you may experience some problems such as morning sickness. You may also experience some changes to your stoma that you should discuss with your healthcare professional or STN.

Talk with your healthcare professional about your plans to conceive before starting chemotherapy or radiation, because these treatments can affect your ability to have children. In some cases, it may be recommended that either sperm or eggs are frozen in case your ability to conceive is hindered. If you want to have children after chemotherapy or radiation therapy, get as much information as early as you can.



Questions About Your Pregnancy

Intestinal obstruction

Occasionally during pregnancy, some people with ileostomies experience episodes of intestinal obstruction.

This happens when the enlarging uterus slows down or blocks the passage of intestinal contents. As a result, the discharge from the ileostomy stops flowing into the pouch, the abdomen becomes distended, and crampy pain is felt.

Restricting your diet to fluids and resting may solve the problem. However, if the lack of stoma discharge persists and the pain continues, seek help from your healthcare professional. On rare occasions, hospital admission and intravenous fluids are necessary to “rest” the intestine.

Morning sickness

Maintaining adequate fluid intake is important to avoid dehydration, especially if you suffer from morning sickness. Try to eat frequent, small meals and avoid rich, greasy foods. Consult your healthcare professional at once if the sickness is persistent or severe enough to keep you from eating or drinking.

Special precautions

People with urostomies may be more prone to kidney infections during pregnancy. Again, drinking lots of fluids is important. Although your urine will be tested at every prenatal visit, call your healthcare professional right away if you think you have a urinary infection. The doctor may want to do further tests, and will decide if an antibiotic is appropriate for your condition.

If you have a urostomy, it is important not to confuse the normal fine strands of mucus present in your urine with an infection. There may be small amounts of bleeding from the stoma itself. This is not necessarily indicative of an infection.

Prenatal exercises

Attending pregnancy and pre-birth classes is an important part of your prenatal care. There is no reason why you should not take part in the exercises. As your abdomen enlarges, however, certain exercises can affect the security of your pouch. Remember to empty your pouch before the start of the class.

Stoma changes

As your abdomen enlarges and changes, you may need a modification to your pouching system. For example, it may not be advisable or necessary to use convexity.

If you are changing your pouch more frequently than before your pregnancy, you may need to use something different. It is a good idea to consult with your STN. Keep measuring your stoma from time to time, and change the stoma size of your pouch as necessary.

Most people find that soon after delivery, their stoma quickly reverts to its pre-pregnancy size. The skin may be different as the abdomen adjusts, so a pouch adjustment may be needed after delivery.





Ultrasounds

The large amounts of oil or gel used in routine ultrasound scanning can seep into the tape or skin barriers which can prevent or cause adhesion problems. After such scans be sure to clean the skin thoroughly and change your pouch to make sure all traces of oil or gel are removed.

Ultrasound scans may be complicated for those with urostomies, due to the absence of a bladder, which helps to give a clear view of the baby in early pregnancy. Later, scans may be complicated because of the position of a baby in relation to the stoma. When the baby's head is directly beneath the stoma, which is not uncommon, measurement of his or her head is not easy. As an alternative to abdominal scanning, you may be offered a vaginal scan which is also useful in detecting any early pregnancy problems.

Diet

For the most part, diet and other healthcare practices are the same as for people without stomas. A good diet is important in pregnancy whether or not you have a stoma.

Discuss your eating habits with your healthcare professional who will help you decide what diet to follow and monitor your progress throughout your pregnancy. If you know that certain foods upset your system, continue to avoid these and eat a suitable substitute.

Medication

Iron tablets may be prescribed to prevent anaemia. If you find that the iron tablets upset your stomach, ask for a different type of supplement. You may also be prescribed vitamins. Inform your healthcare professional regarding any and all





medications (even over-the-counter) that you are taking during your prenatal visit. Most people avoid alcohol altogether during pregnancy. And of course, smoking can be very harmful for both you and your developing baby.

Labour and childbirth

There seem to be few problems for those with urostomies during labour. If your rectum has been removed, you may worry that you won't be able to have a vaginal delivery. But removal of the rectum is only a problem if there is damage to the nerve supply.

If the rectum has been removed and there is scar tissue in the perineum (the area between the vagina and the original site of the anus), it may be necessary to do an episiotomy. This is a small cut to enlarge the vaginal opening which makes the birth easier and prevents tearing of the vaginal tissue.

Sometimes a delivery by Caesarean section is necessary. If your healthcare professional feels you need a Caesarean section, it will be discussed with you in advance.

Whatever type of delivery you have, your pouch will need to be changed after the birth because of the physical exertion involved in delivery and change in the shape and firmness of your abdomen. Before you go to the hospital, make up a little package with everything you need for pouch changes.

Your abdomen may be quite sore for a couple of days after a Caesarean section.

Breastfeeding

Many hospitals and community health centres have specialised nurses called lactation consultants who can give much needed practical recommendations and teaching assistance. It's helpful to have an empty pouch before feeding, as an active baby could dislodge a slightly full or full pouch or cause it to leak. If for some reason there are breastfeeding problems, contact a lactation consultant for help. To find a lactation consultant nearest to you, ask your maternal health nurse or go to **www.ilca.org**.

Genetics

There is no firm hereditary connection with either Crohn's disease, ulcerative colitis or cancer; however, there is with a condition known as familial polyposis coli (FPC) or familial adenomatous polyposis (FAP). Genetic counselling may be advisable if these conditions exist.



Getting Back to Life

If you want to return to the active sex life that you enjoyed before surgery or an even better one, 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 you are looking for more detailed information on one of these topics, you may talk to your STN or healthcare professional.



Changes in your sex life after surgery can be upsetting and frustrating. These changes are not the ultimate disaster, even though it may seem that way at times. Try to keep it in perspective and remind yourself that you are a person with all sorts of traits and characteristics, talents, and interests. While it can be fun and great, sex is only one part of you.

Whatever your situation, remember to be patient and enjoy the prospect of your healthy, normal post-surgery life with a stoma.

Procuring your ostomy product supplies

Australia

In order to purchase your ostomy products at a subsidised rate, you will need to become a member of a Stoma Association. An annual membership fee is required to assist the association with administration costs.

Stoma Associations purchase ostomy products from suppliers such as Hollister Incorporated and distribute them to their members on a monthly basis. Most of these products are subsidised by the Australian Government. The Department of Health's **Stoma Appliance Scheme (SAS)**, established in 1975, improves access to the most suitable and clinically appropriate stoma-related products.

The **Australian Council of Stoma Associations Inc. (ACSA)** (website www.australianstoma.com.au) represents, at a national level, the interests of 21 regional Stoma Associations and approximately 46,000 people living with ostomies throughout Australia. The ACSA liaises with the Australian Government in matters related to accessing products funded through the SAS, coordinates ostomy-related support services, provides advocacy for people living with stomas, and publishes the national journal, *Ostomy Australia*.

1. How to order your ostomy products through the Stoma Appliance Scheme (SAS)

Once you become a member of a Stoma Association, you will be able to obtain your ostomy products at a subsidised rate. The Association will provide you with details on how to place your monthly order.

Access SAS Forms

www.australianstoma.com.au/associations

Your STN/healthcare professional can help you complete the necessary forms to become a member.

2. How to find a STN near your home

The Australian Association of Stomal Therapy Nurses (AASTN) – (website www.stomaltherapy.com) is a professional organisation of STNs. One of their major objectives is to promote quality care for a wide range of people with specific needs. These needs may be related to ostomy construction, urinary or faecal incontinence, wounds with or without tube insertion, and breast surgery.

The AASTN website provides a “**Find a Stomal Nurse**” feature to help you locate a STN in your State/Area. It also provides a helpful **Managing Your Stoma Supplies** guide.

New Zealand

After surgery, your Stoma Nurse will establish a product fit that is right for you. Supply of your product is organised by your Stoma Nurse, via a distributor.

Useful links:

Australia

Find a Stoma Association Near You

www.australianstoma.com.au/associations

Find a Local Ostomy Support Group

www.australianstoma.com.au/living-well-with-a-stoma/support-groups-2/

New Zealand

The Ostomy NZ

www.ostomy.org.nz

(The Federation of Ostomy Societies NZ) represents, at a national level, the interests of 19 regional Ostomy Societies located throughout New Zealand. Helping ostomates and their families/caregivers feel educated and empowered to lead a normal life is the main focus.

Cancer Society

ostomyasiasouthpacific.org

Crohns and Colitis NZ

www.crohnsandcolitis.org.nz

Resources and Organisations

Your healthcare professional and your STN will be very important resources for you in the days ahead. You also have ongoing access to online information or printed educational materials:

Ostomy Learning Centre

Find useful content that's easy to read and share with others.

Australia: www.hollister.com.au/ostomylearningcentre

New Zealand: www.hollister.co.nz/ostomylearningcentre



Understanding
an Ostomy



Maintaining
Skin Health



Living With
an Ostomy



Using Ostomy
Products

Hollister Incorporated YouTube Channel

www.youtube.com/hollisterincorporated

View a variety of how to and lifestyle videos. Also includes interviews and tips from people living with ostomies.

Australia

Cancer Council of Australia

www.cancer.org.au

Bowel Cancer Australia

www.bowelcanceraustralia.org

Australian Council of Stoma Associations

www.australianstoma.com.au

New Zealand

Cancer Council of New Zealand

www.cancernz.org.nz

Bowel Cancer New Zealand

www.bowelcancernz.org.nz

The Federation of NZ Ostomy Societies Inc. (FNZOS)

www.ostomy.org.nz

Lifestyle Series and Care Tips

Available from your clinician or for PDF download at:

Australia:

www.hollister.com.au/en-au/ostomycare/educationaltools

New Zealand:

www.hollister.co.nz/en-nz/ostomycare/educationaltools

Glossary

Caesarean Section

A surgical opening in the uterus as a means to deliver a baby. Alternative to vaginal delivery. Also known as a C-section.

Colostomy

An ostomy (surgical opening) created in the colon; part of the large intestine or colon.

Condom

A contraceptive device which fits over the penis to block sperm from entering the vagina.

Contraception

A method used to prevent pregnancy.

Crohn's Disease

A disease where parts of the digestive tract become inflamed.

Ileostomy

An ostomy (surgical opening) created in the small intestine.

Infertility

The inability to become pregnant.

Ostomy

A surgically created opening in the gastrointestinal or urinary tract. Also known as a stoma.

Perineum

The area between the anus and the vaginal area.

Peristomal Skin

The area around the stoma starting at the skin/stoma junction and extending outward to the area covered by the pouching system.

Pouch

The bag that collects output from the stoma.

Rectum

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

Skin Barrier

The portion of your pouching system that fits immediately around your stoma. It protects your skin and holds the pouching system in place. Sometimes called a wafer.

Stoma

A surgically created opening in the gastrointestinal or urinary tract. Also known as an ostomy.

Stool

Waste material from the bowel. Also known as faeces or bowel movement.

Ulcerative Colitis

A disease of the large bowel which causes inflammation and bleeding.

Urostomy

An ostomy (surgical opening) created to drain urine.

Wear time

The length of time a pouching system can be worn before it fails. Wear times can vary but should be fairly consistent for each person.

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Customer Service
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The information contained in this brochure is provided as general information only and is not intended to be medical advice. Please see our website for the most up to date information, as guidance can and does sometimes change. Always follow product Instructions For Use and ask your healthcare professional for more information.

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