



let's talk about...
sex & intimacy



specialists in stoma
and continence care

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**This booklet has been
produced in conjunction
with the Community
Specialist Nurse Team at
Respond Healthcare.**

introduction

If you have a stoma or are expecting ostomy surgery, you are probably wondering or perhaps concerned about how you will continue to live your life as “before”, including how you will continue to have sex and build an intimate relationship.

The aim of this booklet is to discuss the potential issues around sex and intimacy following surgery and provide you with information, advice and answers which we hope will help you regain and build your intimate relationships. Because we want to give you clear advice and information some parts of this booklet are sexually explicit. We recommend that your partner reads this booklet along with you, however if you have any further concerns or questions please consult with your stoma nurse or your GP (where relevant).

One thing to be certain of is that anything you discuss with your stoma nurse or healthcare professional will be discussed sensitively and with confidence, no question is a silly question. If you are culturally different from your stoma nurse and wish to discuss sex and intimacy with someone who shares your same beliefs, they may be able to advise on groups or resources that will help – there is a lot of information and resources out there, you are not alone.

We encourage you to start the conversation about sex and intimacy with your partner or stoma nurse as early as possible. Yes, this may be awkward, but communication is key in developing and maintaining an intimate and happy relationship, regardless of sex.

intimacy

Firstly and most importantly, intimacy is so much more than having sex, and is important if you would like to develop or nurture a relationship.

Touching, kissing, cuddling and sharing a bed can all help to provide intimacy that you and your partner need to help regain your sex life. Don't be afraid to open-up and acknowledge how you are feeling. Recognising your feelings and sharing them will help you in your recovery.

Once you have gone through your initial recovery period and feel ready to have sex again do not rush yourself or your partner. Find and discuss with your partner what you feel comfortable with and remember that the intimacy that you share will help you feel more comfortable and confident in the bedroom.

If you have any concerns about being intimate with your partner following surgery please talk with your stoma nurse.

Your emotions following surgery may be intense. Losing control over a function such as going to the toilet may be overwhelming and feel as though you have lost control of your entire body, or that you no longer recognise it. These feelings are completely normal. You are not alone in these thoughts and rest assured that many ostomates feel this way and return to happy, active sex lives in time.

body image

You will naturally wonder how other people will react to you having a stoma - if they can see it under your clothing, what would they think if you showed them, how will you have sex wearing a pouch and so on. Answers to these concerns depend on various situations and the nature of your illness, type of stoma and ostomy surgery, age, gender and the type of intimate relationship you are involved in.

These concerns are completely normal and the good news is that there are many stoma accessories such as flange extenders and support garments available to you to help increase your confidence and provide peace of mind during your intimate moments and everyday life.

Some ostomates find that taking responsibility for their rehabilitation, eating well and building their fitness helps to improve both their body confidence and confidence in general following surgery. Sharing these experiences with someone who matters to you could be beneficial and aid in your recovery.

"My first time being intimate after having my ileostomy was terrifying. I was scared my pouch was going to fall off or that my partner at the time would have said something about it rustling. He did in fact comment about it and it made me scared for a while. After a few months and meeting someone else who has IBD, I realised it's not the bag – it's the person!"

- Alannah



starting the conversation

If you have the opportunity, you may wish to start asking questions and discussing how you will continue your sex life after surgery with your stoma nurse or surgeon prior to your surgery. If not, we recommend that you discuss this as soon as you can as this will help your emotional recovery and help you feel more confident; because after-all once clothes are off the pouch can hardly be ignored.

Your partner may have experienced your illness and surgery alongside you, so they will already be aware of your stoma and what it means to have one. When you get into bed together for the first time, even if not to have sex, acknowledging the presence of your pouch will help to break any awkwardness you both may be feeling and will help your intimacy.

If you are beginning a new relationship and are worried about telling the person about your stoma, try rehearsing a short explanation of how you've come to have a stoma and pouch – this will allow the other person to ask any questions, to help both of you feel more comfortable. It is a possibility that the person may not want to continue a physical relationship after finding out about your stoma, this is their issue, not yours and remember there are countless reasons why relationships do not work out, regardless of having a stoma.

having sex

When it comes to having sex, it is important that you feel comfortable with your partner; talking and trust are key to establishing a fulfilling sexual relationship after your surgery. It is important to consider that the “roles” between you and your partner may have changed; the person who would initiate intercourse may not be the same and there may be some adjustments needed.

It is so important to communicate with your partner and express any thoughts, feelings or concerns you may have, or that they may have. In this section we will cover frequently asked questions regarding having sex following ostomy surgery, which we hope will answer any questions that you have, however you may wish to ask them directly to your stoma nurse and include your partner in the appointment so that they can ask any questions they have too.

FAQ

How long should I wait to have sex after my ostomy surgery?

6 weeks (or longer for women if the vagina has been operated on), or until you feel ready.

Will it hurt?

The first time you have intercourse after your surgery may not go perfectly. For men there may be issues with achieving or sustaining an erection and ladies may experience some pain.

Pain during intercourse is known as Dyspareunia and is thought to be caused by an anatomical change during surgery, leading to reduced sexual desire and arousal. This can be made worse by stress and reduced lubrication, which will be covered on page 12 of this booklet.

Take your time and discuss your feelings or worries with your partner as learning to navigate the bedroom with a stoma following surgery may take some time for some, or no time at all for others! We cover potential issues following surgery on page 10 of this booklet.

Should I avoid certain positions?

The pressure of your bodies will not hurt your stoma. Conventional positions are almost always possible for people with a stoma. If penetration is painful there are other sexual positions that you can try. Many ostomates find that a side-by-side position works well as it allows the pouch to hang down to the side and not come between them and their partner.

Missionary may be uncomfortable for a woman if the rectum has been removed. Instead, an option is for the man to enter the vagina from behind, or for the woman to go on top.

How do I have sex whilst wearing a pouch? Won't it get in the way?

You should empty your pouch before intercourse, and you may also want to try using a smaller version of your pouch; they are designed for those who are active or for intimate moments – but remember they also hold less content and need to be emptied more often so please bear this in mind.

Wearing a top, T-Shirt, stoma belt or pouch cover can help you to feel more confident and that your pouch is "out of the way" and closer to your skin.



"My first time being intimate after my surgery, I was nervous. My first thoughts were "is the bag going to get in the way or make a noise during these times?" I then realised that it really isn't any different than how it was before surgery!"

- Jaimie

What about odour?

If you know you are going to be sexually active, try to avoid "gassy" foods such as beans and cabbages and "gassy" soft drinks and beers. If you have a Colostomy or an Ileostomy, additional pouch filters, such as the Osto Ez-Vent® are available to help control gas and keep the pouch flat.

Should I still use/take contraception?

Any of the common methods of contraception are possible: using a condom, a barrier or intrauterine device, the pill, injection or implant. There is however some evidence that the effectiveness of the contraceptive pill is limited for women with Ileostomies, as it is thought that the pill passes too quickly through the digestive system without being absorbed into the body, meaning the protection of the pill is lost. Please discuss this possibility with your GP or stoma nurse first.

Can I still get pregnant with a stoma?

Many women with ostomies go on to start a family. A vaginal birth is still very feasible should the reproductive organs be undamaged and work normally, however a caesarean section is more common.

Having a stoma should have no effect on your ability to conceive, only pre-existing conditions or if you are undergoing chemotherapy or radiation therapy may affect your desires and ability to have intercourse and conceive. Talk with your nurse if you have any plans to conceive before starting chemotherapy or radiation as they can affect your ability to have children; it may be recommended to have your eggs or partner's sperm frozen just in case your ability to conceive after treatment is hindered; we recommend that you get as much professional information as you can.

potential issues for sexual intercourse following surgery

It is not unusual for people who do not have a stoma or have not had surgery to experience difficulties or issues with their sex lives in their lifetime. It is not a fair assumption to say that all potential issues for men and women with stomas stem from surgery, even if having a stoma becomes the focal point for any problems people have.

There are of course physical reasons behind sexual problems stemming from surgery which we will discuss in this section. Fatigue and loss of libido are common reports of issues following surgery in the early weeks and months. There are also some medications that can stop or delay orgasms; you will need to chat to your GP if you have any concerns.

Remember to take your time and only do what you feel comfortable with, developing your intimacy is crucial during this time and will help you overcome any issues along the way.



"In the 7 years I have been an ostomate, I am glad to say that neither me or my wife have had a problem regarding sex or intimacy. If anything I was a little eager after getting home and burst some stitches! My advice for ostomates is that if you and your partner are in love you see each other, not a bag. An ostomy changes nothing"

- Keith

issues for men

For men, the most common issue following surgery is impotence; the inability to achieve or sustain an erection long enough to ejaculate or climax. There are many causes or reasons behind impotence, and it is not limited to people with stomas.

The risk is that the nerves that control an erection and ejaculation can be disturbed during surgery. The nerve pathways run close to the rectum, and if damaged can cause the ability to have an erection to be wholly or partially lost.

Temporary impotence is common following stoma surgery, the healing process can sometimes take a long time so do not be too worried if within a couple of months after surgery you are experiencing impotence – it can take up to two years before it is clear whether it is permanent, or if the sexual function will come back.

If you are concerned about the possibility of impotence please talk to your surgeon or stoma nurse, and if you are experiencing impotence and worried about your partners reaction, try to explain that it is due to your surgery and reassure them that it has nothing to do with them. Communicating with your partner will make dealing with impotency much easier for you and remember you can still create intimate moments without having sex.

If you are undergoing further treatment, such as chemotherapy or radiation therapy, these can also affect your ability and desire for intercourse.

Please also remember that lifestyle can play a big role in both causing and contributing to impotence. Lifestyle issues include having intercourse when tired, using drugs and/or alcohol, smoking, and worrying about intercourse can all have an effect.

issues for women

Many issues discussed below are related to a specific type of surgery and may not apply to you. Always talk to your stoma nurse if you are concerned with any of the issues discussed below and talk to your partner too.

- A very common problem for women following (but not limited to) stoma surgery is vaginal dryness, making intercourse difficult and uncomfortable. Vaginal dryness may also be a side effect from medications, your doctor should be able to advise on this.
- Penetration may also be painful or uncomfortable due to scarring of tissues following removal of the colon or bladder.
- When the rectum is removed in surgery, this leaves a Perineal wound (the Perineum is below the anus and in women extends to the vaginal opening and in men extends to the base of the testicles). The wound can remain tender for a while after surgery and sexual intercourse can be painful.
- Another problem women with a stoma can face is that when the colon is removed it sometimes allows the uterus to shift backwards, causing pain during intercourse.
- Some women also find a decreased feeling or sensitivity of the clitoris, which may be due to the nerve pathways to the clitoris being damaged in surgery.

It is very important to remember that not every woman with a stoma will have these issues, nor are they solely derived or as a result of stoma surgery. There are some solutions for these problems, for example, for dryness try a lubricating jelly or a lubricated condom, where applicable, and for a perineal wound, reconstruction surgery may be possible. If you have any concerns or would like further advice please consult your surgeon or stoma nurse.

LGBTQ+ community

Having intercourse whilst having a stoma is not in itself more problematic for the LGBTQ+ community.

However, the potential removal of the rectum in surgery may be an issue for a gay man, or anyone who uses their rectum during intercourse.

Removal of the rectum and anus depend on the type of disease, its extent and the risk of life to a patient, which is based on clinical judgement. It is important for a gay man to discuss this with the surgeon prior to surgery, where possible, so that the possibility of keeping the rectum and any risks associated can be discussed. If the rectum is partly removed it should be completely healed before any attempt of penetration.

Important note for all ostomates: The stoma must never be used for sexual penetration. This risks damage to the stoma most likely resulting in more surgery.



summary

We hope this booklet has provided you with information regarding potential issues around sex and intimacy and has answered some questions you may have had. There are plenty of resources available to you if you require any more advice or have any more questions regarding sex and intimacy. In the first instance please consult your surgeon or stoma nurse.

Please remember that there are many factors that can prevent a person from engaging in sexual intercourse. This is not the end of the world (although you may feel like it), and there is much more to you and your intimate relationships. Take it slow, find out what you are comfortable with and enjoy building intimacy with your partner.

Remember, sex is not everything, you, your health and wellbeing are.



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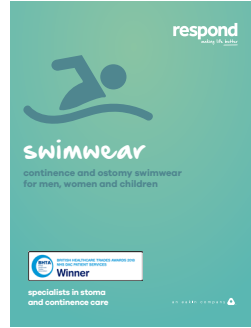
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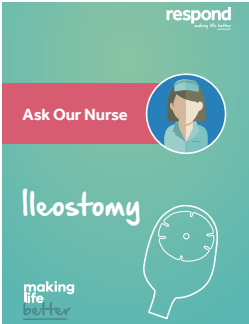
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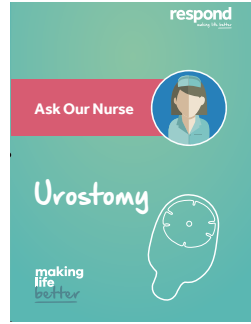
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