



What about sex?

For people with a stoma and their partners



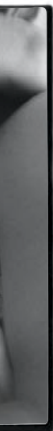
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Sexual pleasure

This booklet is intended to provide support if you have a stoma or live with someone who does – be it a colostomy, ileostomy, or a urostomy. It contains frequently asked questions and answers regarding sexuality.

No matter whether you are young, old, married or single, and regardless how active or inactive your sex life is, a stoma is a major change. For you, as well as your present or future partner, accepting life with a stoma is of major importance to your quality of life.

A satisfying sexual relationship helps us feel good, adding to our physical and emotional well-being. However, developing and maintaining a good sexual relationship is not always easy – whether you have a stoma or not.

Sexuality is probably the most neglected aspect of rehabilitation after surgery. Only in recent years has sex been brought slowly out in the open. Most people undergoing stoma surgery are concerned that having a stoma may threaten their sexual attractiveness and the opportunity to have a satisfying sex life. Doctors, nurses and patients often hesitate to talk about this aspect of stoma surgery. Consequently you may continue to worry unnecessarily, while the questions remain unanswered.

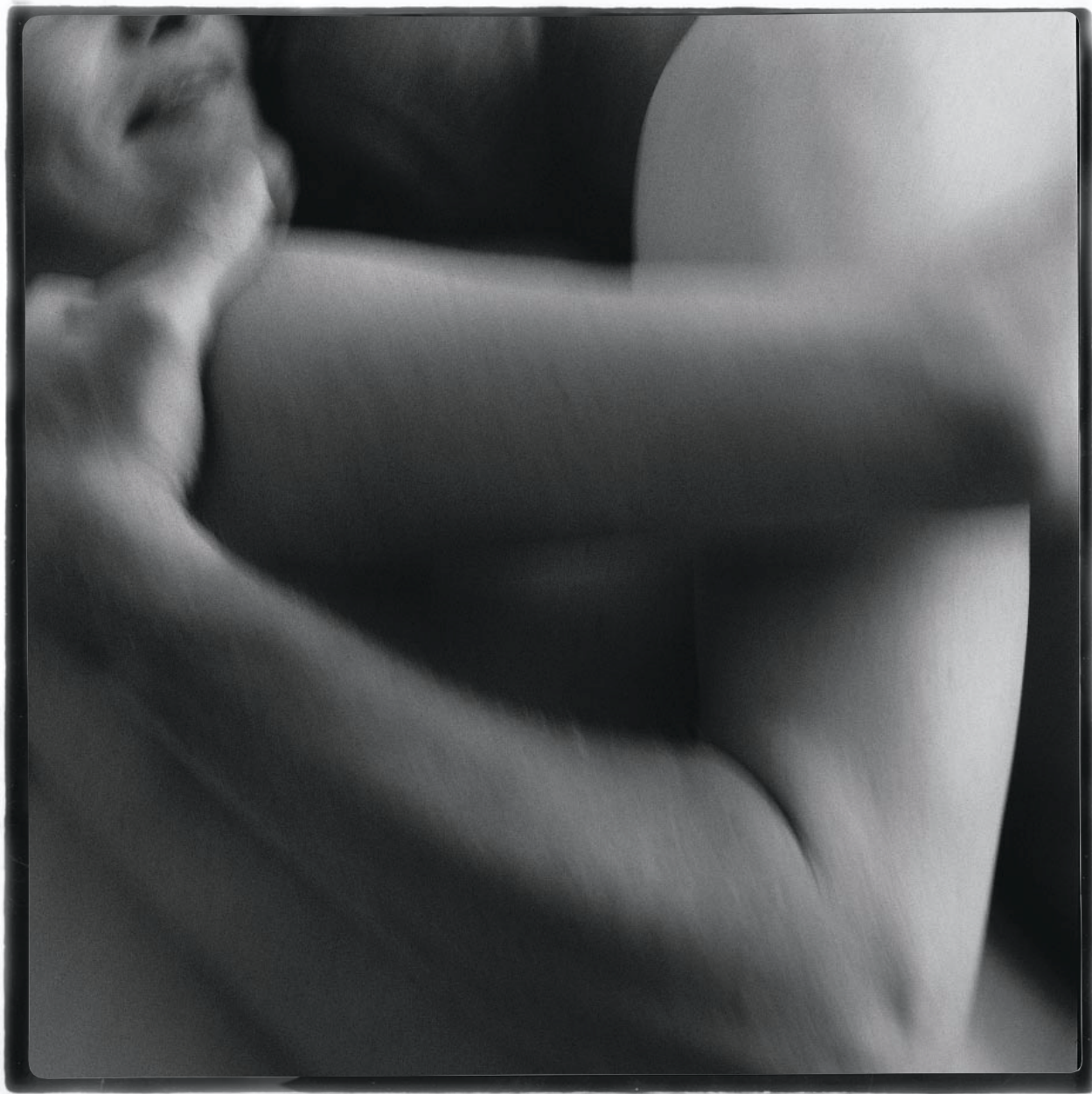
Sexual activity is one of the normal functions of everyday living and as a person with a stoma you should expect to enjoy your sexuality as you did before surgery.

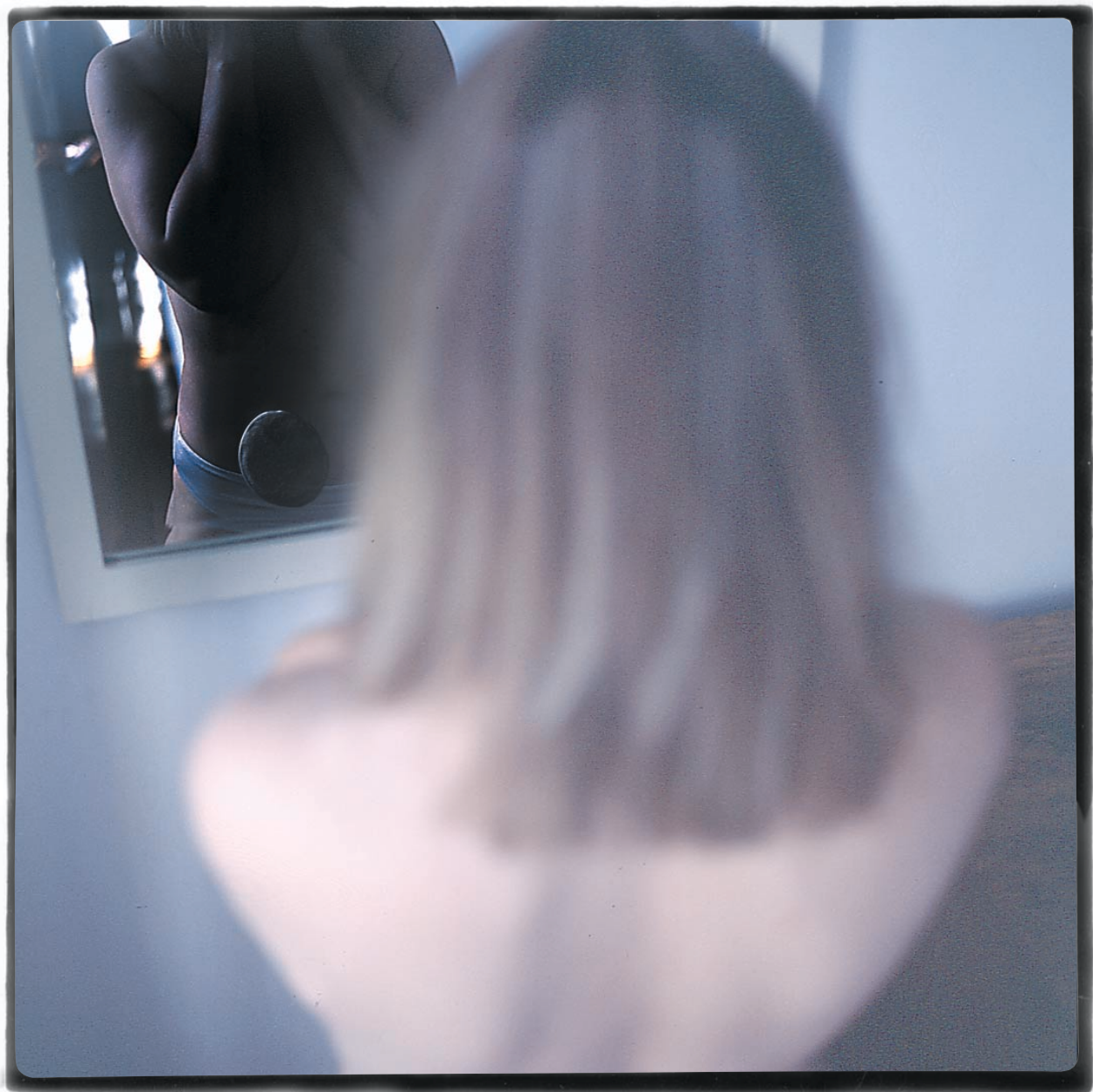
This booklet describes some of the most common problems that people with stomas may encounter when dealing with sexual activity and relationships, as well as possible solutions.

In this booklet we offer information that may be helpful with:

- Coming to terms with yourself, your sexuality and sexual activity now that you have a stoma.
- Management of your stoma in sexual relationships, whether you are a man or a woman, single or married, old or young, heterosexual or homosexual, with a colostomy, ileostomy or urostomy.
- Coping with sexual problems experienced by some people, either as a result of the underlying disease or as a result of the surgery that was required to treat the disease.

As this booklet will not answer all of your questions, we have included a resource list for further information.





Body image

Our body image is the way we see ourselves - the feelings and attitudes that we have towards our bodies.

Most changes in body image take place gradually over a period of time, as in ageing, so that the changes are easily incorporated into the picture we have of ourselves. However, surgery resulting in the formation of a stoma means a sudden, major change in your body and the way you see yourself. It is not a change you wanted or asked for. Even if your surgery has brought an end to years of illness and discomfort, or it has been done to cure a life threatening disease, it still represents the loss of a natural body function and a change in the way you see yourself.

It will take time to get used to this change. It is natural to experience sadness and grief while you adapt to the new, but not really so different, you.



"My friends thought it was something like a garden hose."

I have been in and out of hospitals and had so many operations that I can't count them all. Fortunately, we humans have the ability to repress negative things and to look forward. Personally, I'm looking forward to starting my new education in occupational therapy. I have decided to let people around me know I have a stoma. My stoma is demystified once and for all. And that's exactly what I want.

Rikke, 27, has had an ileostomy since 1999.

Recovery

It is natural to be concerned about your own well being and health during your convalescence. However, preoccupation with yourself will worry your partner, family and friends. They need to know what to expect from you, particularly if it involves intimacy and sex. It is also important that you are sensitive to the feelings of your partner, so you can understand each other as well as possible.

During this period, you will probably experience a wide range of emotions that can change very quickly. You may want to be held and cared for. You may want to just touch, kiss or fondle your partner. You may not want to have anything to do with anyone. Tell important people in your life how you feel. Tell them that as soon as you begin to feel better, you will be willing to explore friendship, love and intimacy again.

Returning home after surgery is a time for healing and recovery, which may take priority over sexual adjustment. Yet there are specific things you can do to help yourself adjust sexually:

- Share your thoughts and needs with your partner.
- Continue to sleep together. Tell your partner the most comfortable position for you to lie in.
- Allow yourself to be touched and held. Affectionate touching can be very positive and reassuring during recovery.
- Show that you appreciate a warm and loving relationship. By remaining intimate and discussing issues openly, it is often easier for you and your partner to accept life with a stoma.

On the other hand you may have begun to focus on sexual feelings while still in hospital. Both are normal.

Touching, caressing, warmth and affection are all important. We all want to be loved and appreciated.

Anger and fear

After surgery, it is normal and natural to feel anger, fear, and the need to be left alone. You are angry at having an illness, and having to have surgery. We all tend to take feelings of anger out on the people closest to us.

You may have underlying fears that are hard to express; fear of the unknown, change in body function, loss of your life, your attractiveness, fear of being unable to engage in sexual behaviour.

You may be afraid of pain, or of damaging yourself or your partner when you first make love.

Since sexuality is intimately tied up with feelings about yourself, it is important to recognise these emotions of fear and anger and sort them out or they may lead to resentment and feelings of rejection. These feelings may lead to resentment and feelings of rejection. You may remain distant from the very people you care for and need most, and who care for you.

If you have doubts or questions, it is important to talk to your surgeon or stomal therapy nurse, who, if they cannot help, will refer you to someone who can.



Sexual desire

As a result of surgery you are forced into dealing with your body in new ways and into talking about things you have never needed to discuss before. Your sex life is one of these things.

Sexuality is as natural to you as your need for food, for pleasure and for rest. It is usually one of the first needs to change when you are in pain, anxious, depressed or grieving. Illness, medical treatment and surgery often reduce sexual desire as do pain, medication, depression, tiredness and feeling "off colour". After surgery, while you are recovering and learning to manage your stoma, you may not experience any sexual feelings for days, weeks or even months. It is very important therefore, that you be very patient and kind to yourself and your partner. When you are rested, healed, reassured and you have grieved, your sexual desires will return.

You may have feelings of shock and revulsion until you get use to your stoma, how it works and how to manage it. You may feel "different" or abnormal and unacceptable, fearing that your appliance smells, that the stoma is obvious to everyone, or that it makes you less attractive than you were before surgery.

Several things may make sex more difficult in the immediate postoperative period e.g.

- Anxiety or fear about your ability to perform sexually, the attractiveness of your body, the possibility of odour, or that the stoma bag might come off.
- Attempting intercourse before your strength and confidence have returned after the operation.
- Depressed mood, which many people experience following major surgery.
- Medication and alcohol.

Inability to have an erection, pain during intercourse and lack of interest for these reasons are not unusual and are usually temporary. The experience can be traumatic and frighten you into believing that your sexual desires and arousal have disappeared forever. It is important that you and your partner understand this, so that you will both keep calm and not be alarmed if difficulties occur. Remember humour!



Accepting life with a stoma

It may be several weeks or months before you feel entirely comfortable with a stoma. It is important to be frank with each other and understand that acceptance may be gradual rather than immediate and will happen at different times for different people.

The stoma often causes more embarrassment and distress to the person with a stoma than to their partner. Take time to be with those you love and share your concerns with them.

"It's like being on holiday!"

The right appliance can make a world of difference to your quality of life. I know. The area around my stoma is a nightmare of a deep valley, folds and other crevices.

A new appliance gave my skin a chance to rest and heal.

I feel so much more secure. It's like being on holiday! You cannot imagine the relief – how much better my life is!

David, age 57, colostomy since 1971



Talking about sex and your stoma

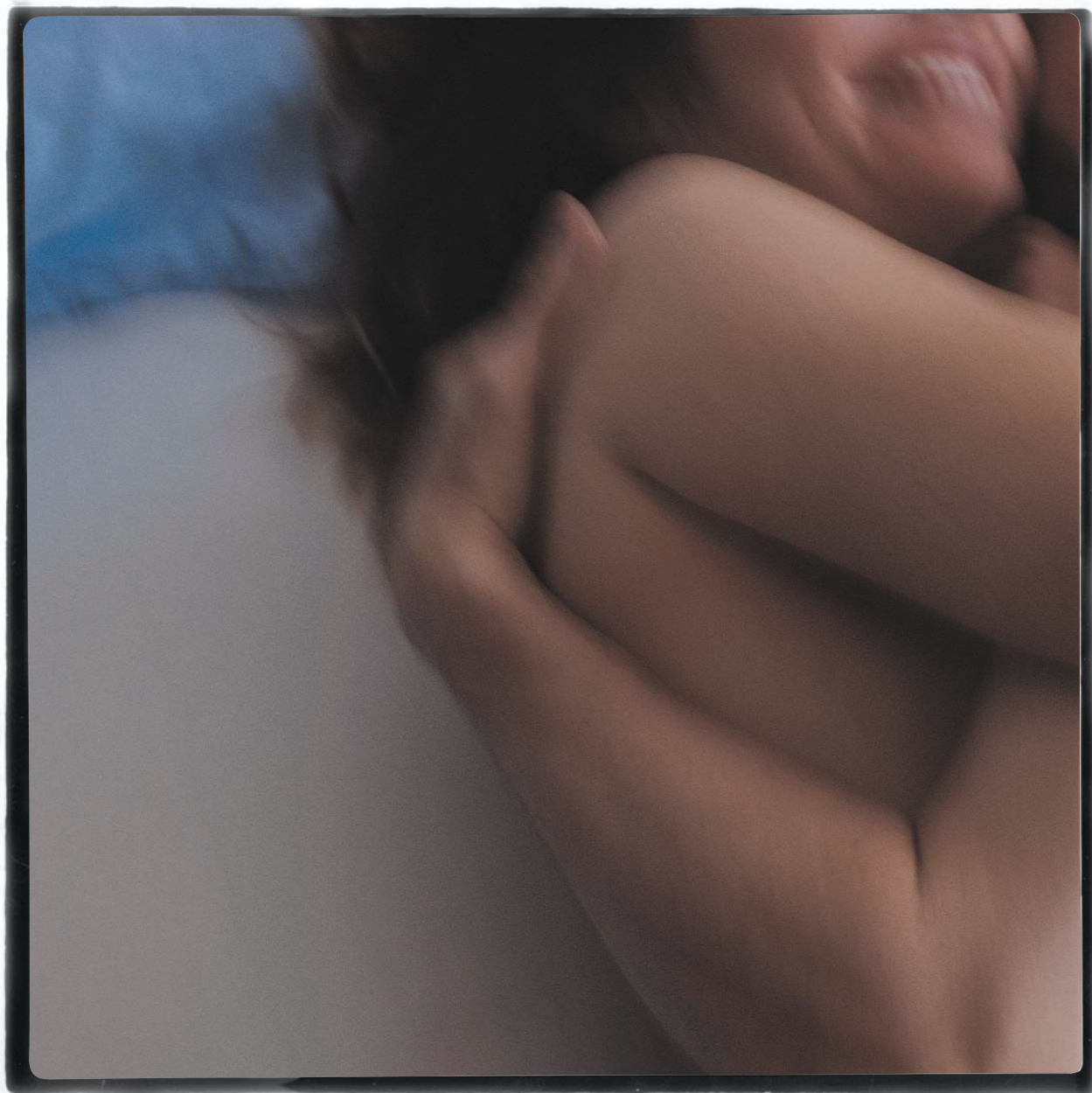
Most of us have difficulty in talking about sex. Often the biggest block to talking about sexual relationships is not knowing what you want. Are you clear about male and female sexual functioning?

About what your surgery entailed? Ask questions!

Do you know what “turns you on”? Do you know what arouses you? What do you enjoy?

We cannot read each other's thoughts. Asking questions and asking for what you like best sexually can perhaps seem selfish. However, helping each other understand is not selfish. Saying what you like is also explaining that your sexual needs are important. As long as you give this information in a kind and understanding manner, it shows that you are anxious to have a good sexual relationship with your partner. Naturally, it is important that you are correspondingly responsive to your partner's desires, and encourage him/her to discuss them, too.





Preparing for making love

You may like to wear a cover over your appliance to prevent the plastic clinging to your skin. Covers can be made in many styles and materials from cotton to sensual satin.

When making love, some females like to wear a sexy mini-slip or short nightgown: crutchless underwear can be purchased in many places (or made if you are handy with a needle and thread). Males may like to wear a cummerbund, nightshirt or undies.

Remember, a birthday suit is very attractive!

It is usually safer and more comfortable to empty the appliance before intercourse. It is usually safer and more comfortable to empty the appliance before intercourse. Prepare in your usual manner; soft light, romantic music, or whatever suits you.

When making love, you and your partner might be afraid of hurting the stoma or dislodging the appliance. Intercourse will not harm the stoma and, as long as you have put on your appliance securely, whatever positions you choose should not affect the stoma bag or the cover.

Allow your partner to feel the appliance or covering if he/she wishes. You might decide to shower together – if your partner wants to see the stoma or touch it let this happen as naturally as looking at or touching any other part of your body. Do not force your partner, but assure him/her that it can be done. Do not mistake your partner's concern for rejection.

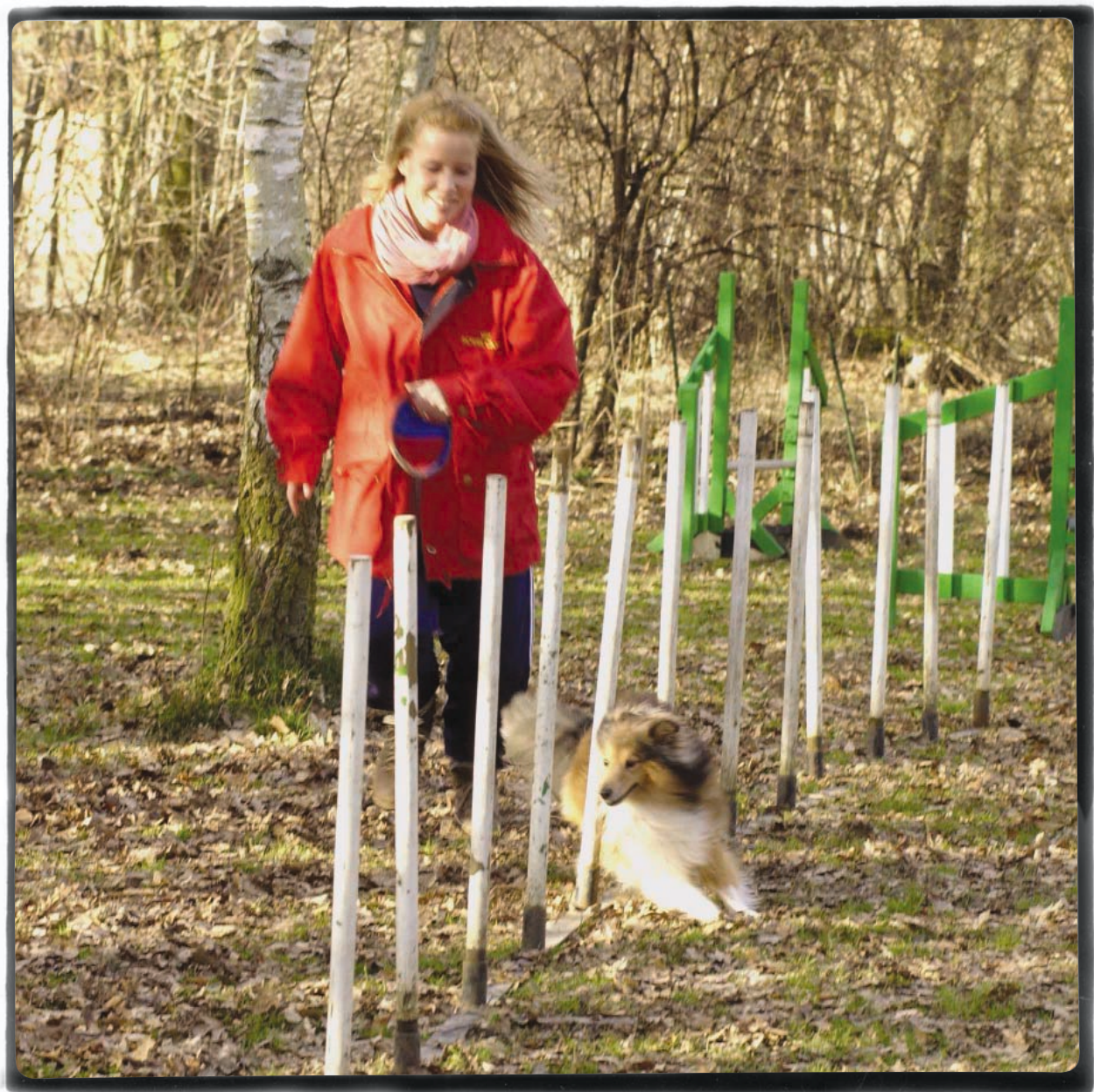
Yes, you can lie on top or underneath your partner – you will not hurt the stoma. Just enjoy!

Humour

Joking about sensitive issues can be very difficult, but it can also make sexual relationships easier.

If something embarrassing happens, the situation can be so much easier to handle if you laugh about it. Embarrassing moments do happen with or without a stoma.





"No obstacle to obstacle racing."

The first days after the operation were personal chaos. I was totally depressed – I had absolutely no will-power – no ability to look forward. However, I was determined to resume my passion for obstacle racing with dogs somehow. But I never even dreamed that my dog and I would place second in a prestigious meet merely four months after my operation. Of course, there are things that are different now. Sex, for example. However, I'm confident that it is only a question of time before I feel confident enough of my "spout" to meet a guy.

Lene, age 29, ileostomy since 2001.



Partners

It is your right to share or not to share information about your body. If you meet someone you would like to have a sexual relationship with, you need to decide when and how much you want to tell about your operation and stoma.

Since there is no right or best time to tell, you need to use your own judgement. However it may be better to tell them early in the relationship, prior to a first intimacy. This may make things easier and help you relax. People with stomas have relationships, marry, have children, and lead normal lives. Relationships involving a person with a stoma are just as stable as relationships in general.

Most partners accept a stoma with a mere "so what? It's you I love", or, "it makes no difference to me," which are very reassuring. Express appreciation of your partner's acceptance of your stoma in the same way you show you are grateful for the other nice things he/she does for you. Being accepted the way you are feels good, and it is natural to respond with normal warm behaviour.

A partner may want to discuss the surgery with your doctors and stomal therapy nurse. Just as it took time for you to adjust to the idea of yourself with a stoma, it may take your partner time to adjust. However, everyone experiences rejection at some time in life. Rejection is not a pleasant experience and it may be extremely painful.

We are not attracted to everyone we meet, nor is everyone attracted to us. Even in established relationships, feelings of attraction change and some relationships end. A positive step in dealing with your feelings when you experience rejection is to acknowledge the fact that you feel disappointed, hurt, sad, angry or depressed. Surround yourself with caring friends and supportive family members. This can be very comforting when you are feeling rejected. Leading your own life, filled with people and activities you enjoy, restores positive feelings about yourself as you rebuild the confidence necessary to start again.

Pregnancy

If you have a stoma and want to have a baby, it is important to talk with people who can advise you – your doctor, your gynaecologist, and your stomal therapy nurse.

Generally, if there are no other problems, there is no reason why you cannot have a baby. Having a stoma does not prevent you from becoming pregnant and giving birth normally. Most doctors recommend a waiting period of approximately one to two years after surgery before conception so that everything inside you can settle down properly.

Having a stoma will not prevent you having "normal" stages of pregnancy, including morning sickness and backache! The stoma may swell and protrude more than usual in mid pregnancy but tends to return to its previous size after delivery.

The effect of birth control pills may change, depending on your surgery and the type of stoma you have. Contraception should be discussed with your surgeon, gynaecologist, gastroenterologist or stomal therapy nurse.





Physical effects

Everyone tends to feel vulnerable and weak after illness and surgery and you are probably no exception.

Medication, hormones, chemotherapy, radiotherapy and your general condition can alter your desire and response to sex.

Certain medications given for pain or to stop you feeling sick can lessen your desire, but so do the symptoms they treat. Generalised tiredness caused by your illness, discomfort following surgery and scar tissue may alter or lessen your sexual response.

Sometimes it happens, but sometimes it is a disappointing fizzer!

Since bowel and bladder surgery are generally associated with the removal of part of all or one or more organs in the pelvis, sexual function may be affected.

If you are a woman and your rectum was removed during surgery there may be a different sensation in your vagina when you are making love. There may be pain, vaginal tenderness, dryness or vaginal discharge for some months. Don't be embarrassed or worried. There are many remedies for the problem. One solution could be a water soluble lubricant. Another simple solution might be a change of position during intercourse. If these do not work, discuss the problem with your doctor or stomal therapist. A suppository, treatment with a



hormone replacement or an oestrogen cream may be suggested.

Some men may experience difficulty in getting an erection. Because the nerves all lie close together, there is a possibility that the nerves involved in sexual function may be damaged during any pelvic surgery removing the rectum, bladder or prostate.

However, it has been said that sex is 95 percent mental and 5 percent physical. You should always consider psychological factors before jumping to the conclusion that you have suffered damage during surgery.

If you are unable to get or maintain an erection, see your surgeon, as there are a number of different ways in which you can be helped. Your surgeon will be able to explain about the range of possibilities available e.g. medication, injections or implants.

If you are homosexual, the closing of the anus may be a problem for you and your partner and may require a lot of adjustment. Intercourse via the stoma can be dangerous and sexually transmitted diseases can be transmitted through the stoma. Understanding, communication and warmth between you and your partner are vital. If necessary, a stomal therapy nurse can refer you to an appropriate counsellor.

May I ask questions?

You should ask whatever questions you have no matter whether you think they are important or silly. It is easy to forget the questions you wanted to ask, so it is a good idea to write the questions down as you think of them and take the list with you when you visit your surgeon or stomal therapy nurse. It may also help to write down the answers you are given.

Don't hesitate to ask! Never be shy about asking questions. If you need more time for your questions, make another appointment. Asking questions is always better than worrying. If you don't ask, you may not get the information you want. Doctors cannot know what particular thing is worrying you unless you tell them.



*Whether you choose friendship, sex, marriage,
or all three, remember that you are still the
same person you were before the operation.*

Explore life and love!



Questions you might want to ask

- How soon can I have sex?
- Will I ever feel normal again?
- Does it make any difference what position we use?
- How long will it be before I can get an erection again?
- Can I have children?
- When will I feel like having sex again?
- Does it take longer for a woman than a man with a stoma to want sex again?
- Can we have sex without having intercourse?
- I'm single. Will anyone ever want to have sex with me?
- Can I get any information about finding a stomal therapy nurse or sex counsellor?
- What sort of problems can we experience during intercourse?
- It hurt when we had intercourse. Why?
- I feel like my relationship has changed. Why?
- What kind of contraception should I use?
- Should I do anything to protect my stoma? If so, what?
- Why can't I get an erection?

Suggested Reading

Comfort,A. (1996) *The Joy of Sex* (5th ed) London: Mitchell Beazley

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Zilbergeld,B (1999) *The new male sexuality* New York Bantam

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Glossary of terms

anus: the entrance to your back passage

chemotherapy: drugs given to cure or control some cancers

colon: bowel (large intestine)

colostomy: this is formed from the colon (large intestine or large bowel), brought out through an opening on to your abdomen. The output (faeces) will vary from a thick fluid to a consistency from mushy to formed.

faeces: bowel motions or stools

gastroenterologist: a doctor who specialises in treating the digestive organs

ileostomy: this is formed from the ileum (small intestine or small bowel), brought out through an opening to your abdomen. The output (stool) will vary from a thick fluid to a consistency similar to toothpaste.

impotence: inability to maintain an erection

penile implant: mechanical stiffener for the penis

rectum: the back passage leading via the anus to the outside of the body

stoma: surgically formed opening into the body

stomal therapy nurse: a nurse who is specially trained to care for people with stomas

therapy: treatment

urostomy: this is formed by isolating a small piece of ileum and implanting the ureters (tubes from the kidneys) into it. One end of the piece of small bowel is brought out through an opening on to the abdomen as a stoma. Urine flows down the ureters from the kidneys, through the piece of bowel (conduit), and out through the stoma.

Your own notes

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