

Sexuality and intimacy following gynaecological cancer treatment



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Esperanza asked Hilde Toelen and Inge De Clippeleir to give a brief overview of how a gynaecological cancer diagnosis and the subsequent treatment affect sexuality and intimacy.

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1. INTRODUCTION

Getting diagnosed with cancer and having treatment can affect your intimacy and sex life. But not everyone is affected in the same way. Various factors play a role, such as the extent of the cancer, the treatment(s) you are undergoing, the emotional strain, whether or not you are in a relationship, and if so, how good that relationship is, your age, your physical condition, how important sexuality is to you and within your relationship...

In this brochure we highlight some effects that are specific to the treatment of gynaecological cancer and that (can) have an impact on your sexuality.

Be aware that you may experience things differently, because every story, every woman, and every partner is unique.

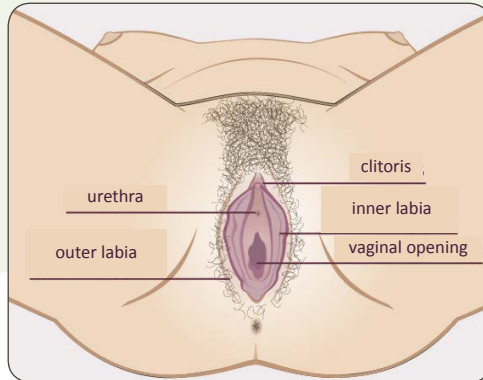
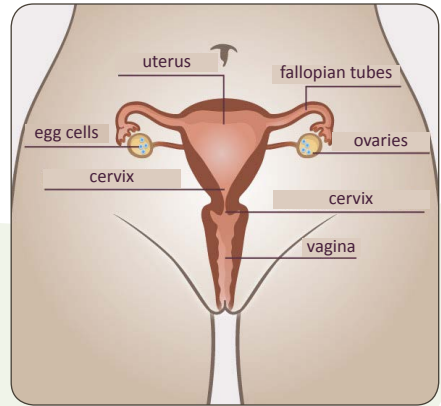
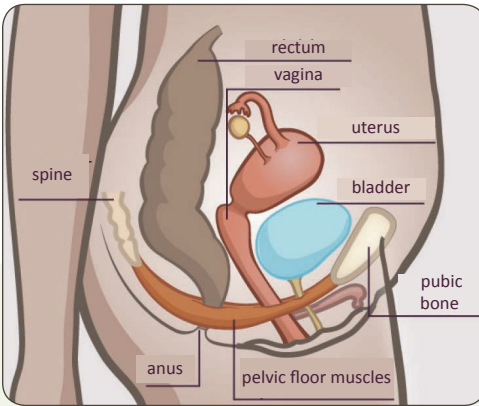
Yet we hope that this brochure will give you better insight into this topic and encourage you to talk to your doctor and your partner.

Cancer of the genitalia, and especially its treatment, often has a direct — and sometimes an indirect — impact on your sexuality.

TIP

Ask your doctor for clear information about the effects of your treatment. Don't hesitate to discuss your concerns.

To start off, it might be helpful to familiarise yourself with the female anatomy. Below you will find some drawings of the female sexual organs, as well as a list of the different treatments and their possible side effects on your sexuality and intimacy.



External and internal sexual organs / allesoverseks.be®

2. YOUR BODY

2.1 SURGERY/OPERATION

a. Ovariectomy

removal of the ovaries

The ovaries are important because they produce many hormones. When both ovaries are removed, oestrogen levels drop sharply and you enter menopause.

Once you have entered menopause, the vaginal mucosa becomes less thick.

This in itself needn't be a problem. If before menopause you would get wet easily and sufficiently, you may not notice this change.

If you had difficulty getting wet even before menopause, you may struggle even more now.

TIP

You can read more about menopause, how you can live with it, how you can handle the side effects better in the ENGAGE Menopause after gynaecological cancers brochure: <https://engage.esgo.org/brochures/menopause-gynaecological-cancers/>

Maybe you were already menopausal. In that case, you will probably see minimal differences. You may experience a change in terms of libido (sexual desire). However, this very much differs from one woman to the next. Some women notice an increase in libido while others see a decrease.

If you are younger, infertility can be an important issue for you caused by ovariectomy. If you don't have children yet and want to, be sure to talk to your doctor about your options. Of course, whether there is a chance to preserve fertility depends on the stage of the gynaecological tumour and the treatments. Be sure to confirm to yourself that your life is the most important thing right now.

Loss of libido is a pretty common problem in cancer survivors, due to side effects of treatment, hormonal imbalances, and stress. During the time of diagnosis and treatment, many women feel as though they are in "survival mode" meaning sexual feelings and activities are not a priority.

The time will come after treatment, when your situation will return to normal, even though many circumstances may have changed. When this happens and sex reappears, you may face, among other things, that your libido has decreased. This is a completely normal part of the process you are going through and it is important to know that you are not alone.

TIP

You can find our Loss of libido after cancer brochure here: <https://engage.esgo.org/brochures/loss-libido-cancer/>

b. Hysterectomy

removal of the uterus and cervix

When you orgasm, the uterus or uterine muscle contracts (along with the pelvic floor muscles), which helps produce a pleasant feeling. Once your uterus is removed, your orgasms may become less intense. However, not everyone feels a difference.

If you have had a hysterectomy, your vulva/vagina no longer ends in the cervix, but at the point where the surgeon closed off the vaginal walls. That new end point is called the vaginal apex.

After surgery, some women report a different feeling in the lower abdomen during penetration with the penis or a finger. This is logical since there is now a different end point but it is not necessarily painful. Some women and their partners are afraid to 'disrupt something'. You should know that the vagina is very elastic, especially if it is sufficiently wet. Your doctor will tell you when you can resume sexual contact after surgery. If you respect that timeframe, everything should be fine.

What if, in addition to the uterus and cervix, part of the vagina was removed during surgery? In that case, certain positions may no longer be possible, especially those involving deep penetration, which may feel uncomfortable or even painful. Examples include the missionary or riding position.

It is then advisable to look for positions with less deep penetration, for example the spooning position.

A pain buffer to reduce penetration can be used in addition to proper lubrication and finding a comfortable position that is safe for you. Penile rings are more often used if the vagina has shortened as a result of the treatments. Imagine silicon rings your partner can wear. This provides a stopping point so the penis can only penetrate as far as the ring will allow. It doesn't cause you pain, and your partner's perception is completely preserved. As you can see, today there are several aids to help you and your partner's sexual practice. There is one most important thing in addition to all this, **talk to your partner, have a dialogue between you** on this topic.

“ *Sara: The first time we made love after my hysterectomy was quite exciting. We took our time and used lube to be on the safe side. I was happy that it still felt the same.* ”



c. Vulvectomy

removal of (part of) the labia

The sexual changes after a vulvectomy are different for everyone and depend on the location of the tumour.

- *Removal of the clitoris.* Sometimes only the tip of the clitoris is removed and part of it still remains under the skin. In that case you will find that with deeper stimulation you still experience the same feeling. If the clitoris is removed completely, you are more likely to enjoy a pleasant feeling between the labia, on the breasts, on the neck and so on. You may also be unable to orgasm.
- *Removal of a tumour near the entrance to the vagina.* Through this procedure, the entrance to the vagina may be narrowed. It is important that you discuss with your doctor what your options are after this surgery. Penetration may no longer be possible or only after dilation. The latter should always be done in consultation with your doctor, sex therapist or nurse.

Depending on the extensiveness of the surgery, women may feel mutilated by this treatment. Be aware that it will take time for your sex drive to return. Take the time to accept your (new) self and feel at ease.

“ *Els: When I was told I had cancer of the labia, I was shell-shocked. I had never heard of it. After I got over the initial shock, I asked myself the question, "Am I ever going to be able to have sex again?". My doctor explained everything clearly. Penetration is no longer an option for us, but thankfully it still feels good.* ”

d. Stoma

possibly temporary

A stoma is an artificial outlet from the bowel through the skin of the abdomen.

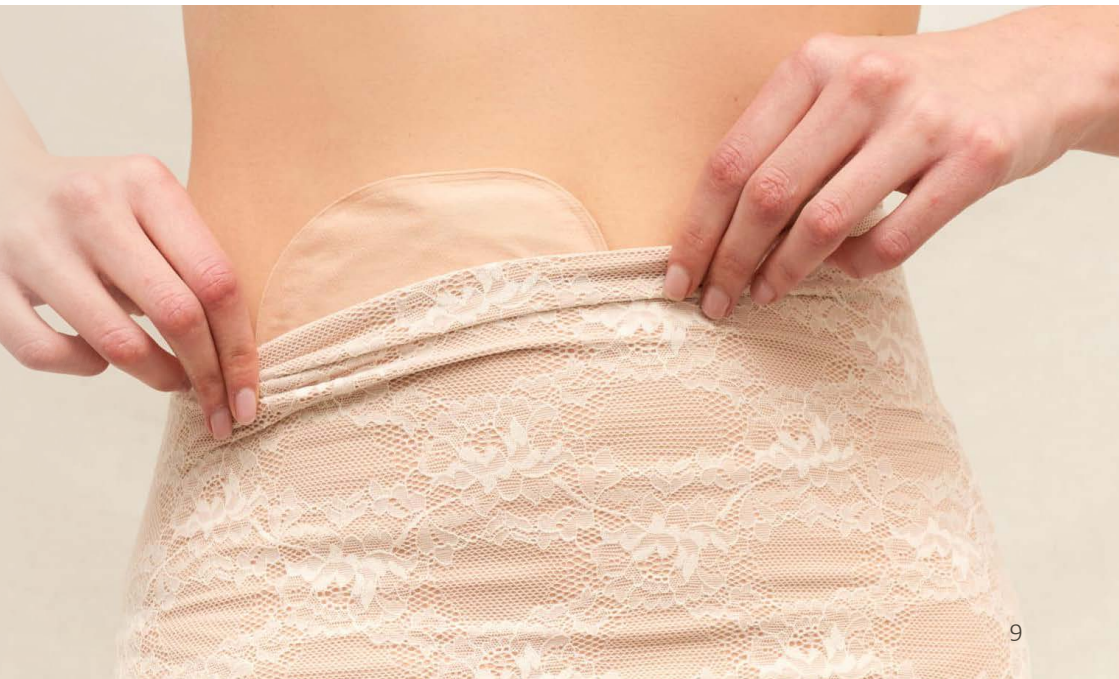
A stoma does not have a sphincter. As a result, faecal matter and urine flow directly into a plastic bag.

Many women have to get used to having a stoma before engaging in sexual contact. It may take a while to get in the mood or take the initiative, or even to assume that your partner does feel like sex. There are many useful aids that can help, such as adapted lingerie.

Because of the damage to the nerves in the lower abdomen, it may take longer for you to get aroused. Many women also struggle to get wet.

TIP

Check online for special lingerie when having a stoma in your own country. There are helping organizations that specifically deal with this area, groups where you can talk with fellow patients. These are worth visiting.





2.2 CHEMOTHERAPY

Chemotherapy can cause physical discomfort (for example, nausea or fatigue) and change the way you look, as you may lose your hair. You may also lose or gain a lot of weight. As a result, many women no longer feel like having sex. However, that doesn't mean you don't need other forms of intimacy, such as tenderness, an extra hug, snuggling up in bed and so on. Talk to your partner about this.

Some women enter menopause (sometimes temporarily) as a result of chemotherapy, which may cause the (vaginal) mucous membranes to be less wet. In that case, lubrication may be useful during intercourse. Extra care, by using a vaginal moisturiser, is also recommended during this period. You are often advised to use a condom in the first few days after chemotherapy. Be sure to check with your nurse or doctor whether this applies to you.

Some types of chemotherapy alter the sensitivity in your fingers (and toes), but sometimes also in other parts of your body. Your fingers are the ultimate instrument to caress and feel. If they have been affected, your ability to 'feel' everything while being intimate may change.

Once you have completed the chemotherapy cycle, your body and your sexual function will recover. But be aware that this takes time. Give yourself the time you need!

TIP

Treatment often changes your desire. You may want less sex but more other forms of intimacy (hugging, caressing, massaging, kissing, etc.). That is normal. Be aware of each other's physical needs to enhance the quality of your relationship.

2.3 RADIOTHERAPY

If the mucous membranes (vaginal or vulvar — between the labia) are damaged by your radiotherapy treatment, you may suffer from skin adhesions or deformities.

There are various forms of radiation therapy. The vast majority of cancer patients receive external radiation therapy, but internal radiation therapy (brachytherapy) and stereotactic radiation therapy are also used.

TIP

You can read more about radiotherapy here:
<https://engage.esgo.org/brochures/radiotherapy-leaflet/>

a. Radiotherapy to the labia

Depending on the radiation dose, the skin may be affected/damaged to a lesser or greater extent. Follow the wound nurse's advice carefully during and after treatment.

- Sex during treatment is often painful and we do not recommend it. Only when you have recovered sufficiently can you slowly start thinking of building things up again. Make sure you take good care of your skin with a moisturiser or protective ointment (ask your wound nurse or doctor for advice).
- You may experience a change in the sensitivity of your labia. Damaged nerves take time to heal (up to 1.5 years). Once they have healed, you will have a better idea of how sex will eventually feel.
- Whether or not you still feel like sex will depend heavily on whether you feel comfortable showing yourself to your partner and whether sexual contact is painless.

Given the radiation damage to the mucosa, it is important to use a moisturiser for care and lube during sexual contact. Depending on the radiotherapy dose and site, penetration may still be possible. Sometimes, however, the skin is too scarred from the radiation. You may still be able to stretch (dilate) the skin at the vaginal entrance, but that is not always possible.

Seek advice from your radiotherapy doctor and/or the department's sex therapist. Stretching should always be done under supervision.

b. Radiotherapy to the vagina and ovary/cervix

Radiotherapy can cause the vaginal walls to scar, making the vagina drier, narrower, and possibly shorter.

c. Radiotherapy to the ovaries

If the ovaries are also in the radiation site, you may enter menopause. That means your female hormones decrease, which can lead to vaginal dryness and thinning of the vaginal mucosa. You may need a vaginal moisturiser for care or lube for intercourse/intimacy .

Depending on the radiotherapy dose and site, penetration may still be possible. Sometimes, however, the skin is too scarred from the radiation. You may still be able to stretch (dilate) the skin at the vaginal entrance, but that is not always possible.

The most common lasting side effects of the radiation are:

- Acute menopause, in which the ovaries no longer function and pregnancy is no longer possible.
- Dry vagina, which can cause bleeding or pain during sexual intercourse.
- Vaginal narrowing, for which regular dilatations can be necessary.
- Change of bowel habits, periods of frequent defecation or even diarrhoea. These side effects may all have an impact on your sexual health.

You may want to start having sex during the treatments. In such cases, proper lubrication and the use of condoms are very important. The vaginal wall is much more vulnerable and if the ovaries have been removed or external radiation therapy has affected them, then more attention should be paid to penetration.

A common side effect after radiotherapy is vaginal adhesions: Due to the inflammation, the vaginal mucosa can stick together. If these adhesions are not resolved regularly, little tissue bridges can build and get more and more solid over time, until they cannot be reopened.

This can be prevented by regularly separating the vaginal walls and dilating. You can use medical devices with different lengths and diameters, so called vaginal dilators to start with. It may be more comfortable for you to use vibrators instead.

But also penetrative intercourse is effective, if tolerable for you. Most importantly, the vaginal canal should be carefully stretched. This might also be helpful to prevent another common long-term side effect, caused by the effect of radiation on the vaginal tissue. A specific form of scarring (“fibrosis”) causes a loss of elasticity, shortening and/or tightening of the vagina over time.

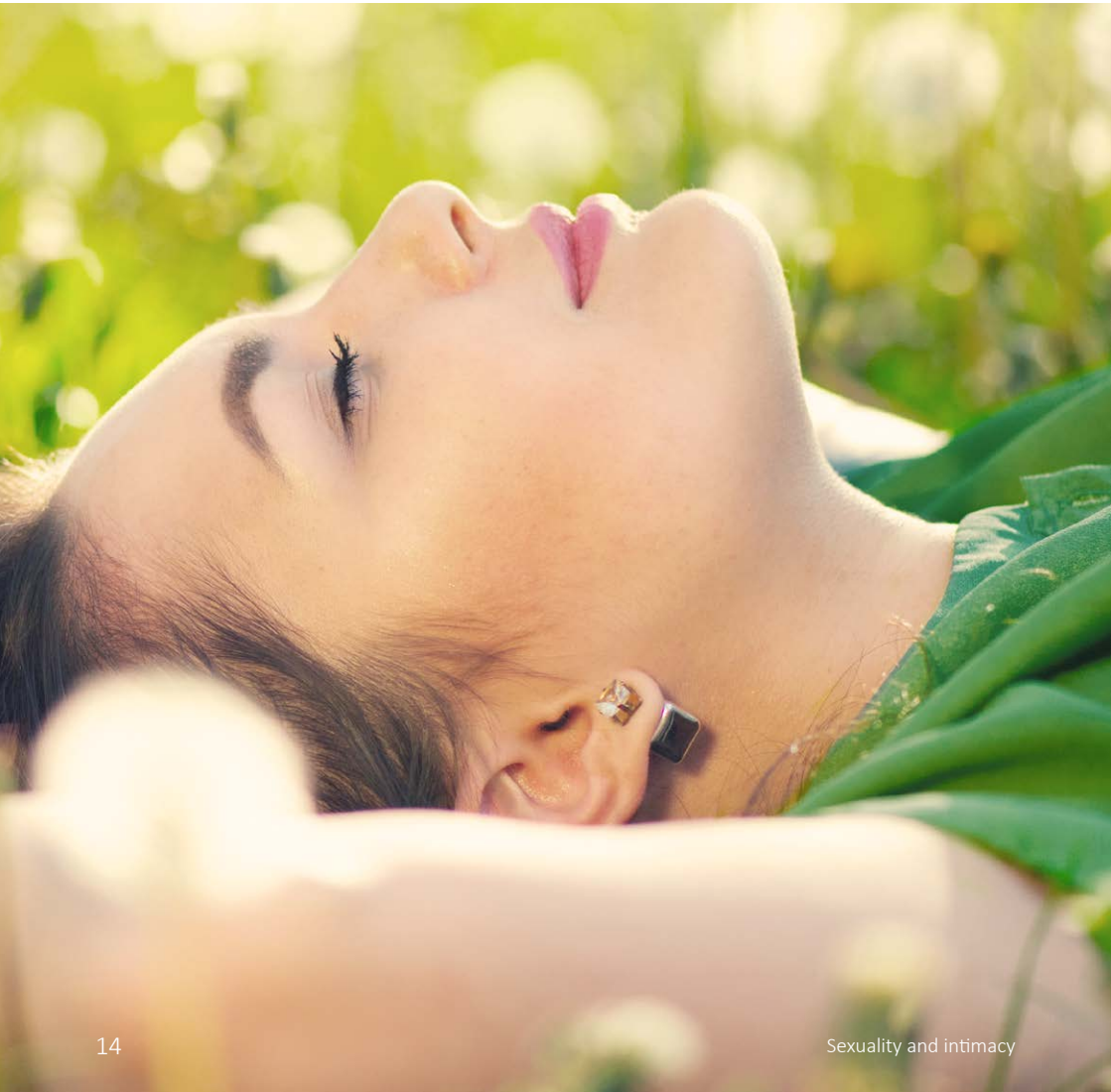
This can lead to pain during intercourse, but also painful gynecological examinations. You should dilate the vagina at least 3 times a week, better daily, for several minutes. Always use a water-based lubricant when dilating to make the insertion more comfortable. Make sure that the full length of the vagina is dilated (stretch gently to the very end), try to gradually increase the diameter to have a good effect. Both dilation and intercourse should never cause pain, but you might experience a feeling of tension or “fullness”. It helps to make some breathing exercises, and consciously relax your pelvic floor muscles.

Seek advice from your radiotherapy doctor and/or the department’s sexual therapist!

2.4 HORMONE THERAPY

Hormone therapy is often given in addition to other treatments. Some cancers are sensitive to sex hormones. By administering drugs that reduce hormone sensitivity, the development and action of the cancer cells can be slowed down or even blocked altogether. Therefore, hormone therapy is often called 'anti-hormone therapy'.

This therapy can affect your sex life: your libido may decrease, you may experience vaginal dryness and/or pain during intercourse, and you may have symptoms of menopause. In this case, it is always recommended to use a vaginal moisturiser 2 to 3 times a week, for care.



3. YOU AS A WOMAN

On a psychological level you may be faced with a variety of **feelings**, ranging from anger to shame, sadness, insecurity, guilt, anxiety, and depression. These feelings can be very overwhelming and throw you off balance or suddenly raise certain life questions. This is completely normal and part of the adjustment process to the disease and its treatment. You often need these emotions to be able to strike a new balance. However, these feelings also cause your sexuality and your libido to take a back seat for a while. With time, the need for intimacy and tenderness often increases again.

You as a woman have a lot to deal with because of the diagnosis, the treatments and their side effects. Your illness and its treatments can cause changes in your **self-image and in the perception of your body**. Above all, allow yourself time and be kind to yourself.

Some common issues you may face during the acceptance process and which may have an impact on your sex life include:

- The effects of the treatment — for example, hair loss, scarring or disfigurement — make some women feel less attractive. If you do not feel beautiful, it is difficult to believe that others do find you attractive.
- For some women, what they lose — for example, the ovaries, uterus, labia or clitoris — equals their womanhood. As a result, they experience a great sense of loss.
- Treatment may also end your fertility. That loss is often accompanied by a great deal of grief and you might find it very difficult to process this.

Dealing with the changes to your body can be tough for you personally as a woman, but it often also raises questions about your partner and their feelings:

- You wonder if your partner still finds you equally attractive.
- You worry about how your partner will react to your body.
- You avoid being touched or showing your naked body.

It is important to take enough time to recover and process everything. Every woman has her own way of doing that. Some express their emotions, others do not. It is about finding what works for you. Have you noticed that you are struggling with your femininity and you feel less attractive, and would like help with this? Don't hesitate to seek advice from a psychologist or sex therapist in your hospital or area.

In addition to respect and trust, mutual understanding, support and communication are the cornerstones of a relationship. If we can't discuss the problems with each other, we won't get ahead. This is also a basic rule in intimacy. The diagnosis of the disease, the treatments, in addition to the physical trials, are a huge mental burden. In a relationship, we go through this together. Patience will be a constant companion in our lives, which is why it is important to discuss everything.

4. YOUR PARTNER



Your cancer diagnosis and its treatment also affect your partner, who is likely to feel powerless. Your partner also needs to adapt to the new situation, which can be quite challenging. In addition, he may need to take on more practical tasks than usual (perhaps temporarily) and at the same time want to be there for his sick partner. Partners may also have questions and concerns. They often struggle to share them because they don't want to be an extra burden.

Thankfully, not all couples experience difficulties in their relationship. Many couples actually grow closer together.

Couples counseling at a sexual therapist is available in all countries. This means that a qualified professional mediates between the two parties and helps them understand the problem from a common point.

5. WHAT IF YOU DON'T HAVE A PARTNER (YET)?

Facing cancer on your own can be quite demanding. You may feel something is missing both for you 'as a woman' and in terms of intimacy, and you find yourself without a sounding board.

Women who may want a relationship in the future often wonder whether their cancer experience will be an excessive burden. They ask themselves a lot of questions. Should I talk about my illness? If so, when? On the first, second or third date? Will my sex life be what it once was?

You may feel very vulnerable sharing what you have been through and expressing your fears on sex and intimacy. We recommend that you only do so when you feel that you can trust the other person.

Usually (new) partners are very understanding, and the initial stages of falling in love definitely help boost their libido.

6. NEW SELF AND RE-DISCOVER SENSUALITY

After the disease, we cannot live as before. It has many aspects, spiritual, psychological and physical. Unfortunately, our quality of life changes in several areas, and at this time we learn and discover ourselves again.

Sexuality is a fundamental element in human life. For some women it is very important, for others not.

If sexuality is an important part of your life then you will have to relearn and reinterpret sexuality after treatment for gynecological cancer. Whether you have a partner or not.

Masturbation, sexual fantasy, and self-care are important, not only to get back in touch with the body and its changes, to re-adjust to physical and mental changes after treatment, but also to evaluate what is pleasurable and what not, to spend time with the new self and re-discover sensuality without pressure.

Sexuality is an expressive and fulfilling tool for romantic affections, love, and belonging, which both parties have to experience.

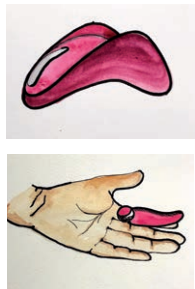
There are several sex toys available, also devices to increase pleasure, increase blood flow for healing effects of the tissue, lubricants and moisturizer.

Today, we don't necessarily have to walk into a sex shop for these. You can also find a large selection online. Take a look, either alone or with your partner.

1.



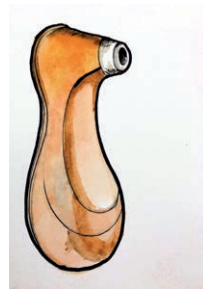
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3.



4.



Modern and high-quality devices have different rhythms and intensity levels, are made of medically tested silicone, are quiet to use, and are often even waterproof and rechargeable.

The modern online erotic industry provides comprehensive product descriptions (regarding material, size, and power supply), and detailed explanations of use. Products are sent discreetly, with outer packaging that does not reveal the contents or the sender.

7. ANNEX: IMPACT ON YOUR SEX LIFE

Below you will find an overview of the possible consequences of your treatment.

	Reduced libido	Vaginal dryness	Shortened or narrowed vagina	Pain during intercourse	Difficulty reaching orgasm
Chemotherapy	Likely	Likely (depending on the type of chemo)	Unlikely (but possible in case of early menopause)	Likely (depending on the type of chemo)	Possible
Radiotherapy to the pelvic area	Likely	Very likely	Very likely	Very likely	Possible
Complete removal of the uterus (radical hysterectomy)	Possible	Likely	Likely	Possible	Possible
Pelvic exenteration (complete removal of the lower part of the colon, as well as the rectum, the bladder, the uterus and the cervix)	Possible	Very likely	Possible	Possible	Possible
Partial or complete removal of the vulva (labia and/or clitoris)	Possible	Very likely	Possible	Possible	Possible (certainly if your clitoris was removed)
Removal (conisation) of a small part of the cervix	Very unlikely	Very unlikely	Very unlikely	Very unlikely (only with scar tissue formation)	Very unlikely
Removal of one ovary	Possible	Very unlikely	Very unlikely	Very unlikely (only with scar tissue formation)	Very unlikely
Removal of both ovaries	Likely	Likely	Possible	Possible	Unlikely
Hormone therapy for uterine cancer (tamoxifen)	Likely	Likely	Possible	Possible	Possible

Table based on <http://bit.ly/1b6vyGJ> (American Cancer Society), adapted and reworked by Prof. Paul Enzlin and Dr. Leen Aerts

8.TIPS

- **General**

- Give yourself time to process your loss and feel like yourself again.
- Ask yourself what you feel like doing. Is it cuddling, caressing, massaging, not going 'all the way'...? When you have figured out for yourself what you are ready for, go ahead and discuss it with your partner.
- Discuss not only your desires, but also your fears and concerns.
- For the partner: you too should express your desires, fears and concerns. We know this often doesn't happen 'because you don't want to be a burden on your sick partner'. But talking will help you grow even closer.
- Try to focus on sexual satisfaction, fun, and pleasure rather than on your libido or on reaching orgasm.
- Your options and feelings are likely to change with time. But remember that different is not necessarily worse. Definitely take your time to (re)discover your sexuality/intimacy.
- Sexual desire often does not come naturally. Try to open up to this idea or see what you need. Do you want to get aroused?
- If you have a partner, ask about his/her feelings and desires. You are two people in this difficult life-situation and both feelings and desires should be acknowledged to understand each other.

- **Pain during intercourse**

- If you are in pain while having intercourse, don't just accept it. Talk to your GP, gynaecologist or sex therapist. Pain can have several causes; your doctor can help determine what the issue is. Often something can be done about it as well, such as using a vaginal moisturiser, lubricant, a hormone or a substitute. Or perhaps you can seek advice from a pelvic floor therapist (if you feel a lot of tension).

- **Referrals**

- Find out if your hospital has a sex therapist. You may be able to turn to them for expert help free of charge.
- Are you struggling with menopause? Speak to your treating physician or a menopause specialist in your area.



Do you have any questions or concerns? Or perhaps you would like to have a chat? Don't hesitate to contact us via

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