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Sexuality and Cancer



The Canadian Cancer Society would like to thank the research teams at the Tom Baker Centre and the University of Calgary who gave us their input, guidance and stories. We also thank the Canadian chapter of the Cancer Patient Education Network for their help.

We are very grateful to the people who shared their personal experiences with us. In some cases, their names have been changed – these names are marked with an asterisk (*).

While many of the stories in this booklet are from people we talked to, some of the quotations are from published material. These sources are listed below:

Beck A. *Couples' Maintenance of Sexual Intimacy after Treatment for Prostate Cancer: A grounded theory study.* [A thesis submitted to the Faculty of Graduate Studies, University of Calgary in partial fulfillment of the requirements for the degree of Doctor of Philosophy, 2011]

Beck A, Robinson JW, Carlson LE. Sexual Intimacy in Heterosexual Couples after Prostate Cancer Treatment: What we know and what we still need to learn. *Urologic Oncology: Seminars and Original Investigations.* 2009;27:137–143.

Robinson JW, Lounsberry J. Communication about Sexuality in Cancer Care. In D Kissane, BD Bultz, P Butow & I Finlay (Eds), *Handbook of Communication in Oncology and Palliative Care.* 2010. New York, NY: Oxford University Press. pp 409–424.

Walker L, Robinson JW. Sexual Adjustment to Androgen Deprivation Therapy: Struggles and strategies. Qualitative Health Research e-publication ahead of print (2011) September DOI: 10.1177/1049732311422706.

Walker L, Robinson JW. Heterosexual Couples' Sexual Adaptation to Androgen Deprivation Therapy for Prostate Cancer. *Psycho-oncology.* 2011;20:880–888.

Walker L. *Heterosexual Couples' Adjustment to Androgen-Deprivation Therapy for Prostate Cancer.* [A thesis submitted to the Faculty of Graduate Studies, University of Calgary in partial fulfillment of the requirements for the degree of Master of Science, 2009]

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Introduction

This booklet is for men and women of all sexual orientations who've been diagnosed with cancer. Their sexual partners may also find it helpful.

“ *There needs to be patience on the part of both partners. Sexuality is not gone – it's just in a different place.* ~ Dan

For many people, sexuality is a personal subject that can be hard to talk about openly. But talking openly and honestly about sex offers you the best chance of coping with any sexual changes that cancer treatment brings. You or your partner may even think that sex shouldn't matter that much right now. It's true that some people don't think about sex while they fight cancer. But it's important to note that sex and all the love and caring that go with it – the connection to another person – can be life-affirming.

“ *Cancer is the beginning of a journey to new definitions and to new realms of what sexuality is.* ~ Dana*

Throughout the booklet, you'll hear from Canadians who speak from personal experience. You may not relate to everything they say, but their stories are offered here to help you understand that:

- You're not alone.
- You can get help if you need it.
- Having cancer doesn't mean that you're no longer a sexual person.

The basics – sex and sexuality



“ *Sexuality is so important to me ... it's about that connection with the person you are sharing yourself with.* ~ Dana*

Understanding sex and sexuality

Sex is generally thought of as an activity. Some people see it as intercourse only. But it can also include things like intimate touching, kissing, cuddling, taking showers together, self-stimulating (masturbating), oral sex and sharing sexual fantasies. Sex brings pleasure and helps maintain intimacy in a relationship.

Culture, family history, values and messages from the media can all affect how we think and feel about sex.

Sexuality is more than the act of sex. It's a part of everyday life that affects how we see ourselves. It includes the physical, emotional, social, spiritual and cultural aspects of a person. Sexuality is as unique as we are, defined by our gender, age, attitudes and many other things. It's tied to our need for closeness, intimacy, caring and pleasure.

Feelings about sexuality can affect our self-esteem, body image, relationships with others and enjoyment of life.

Interest in sex varies a lot from person to person. Some people like to have sex often, and for others, it's only once in a while. Some might not be interested in sex at all. A healthy sex life is however you choose to define it.

When cancer enters your sex life

“ *It's almost like being in a new relationship again. You need to negotiate your way into what feels good for you. A relationship is a living thing and, when you throw something like this into it, requires a lot of care and patience.* ~ Jess*

Cancer and its treatments can affect how you feel about yourself sexually:

- Fear and anxiety about cancer may affect your sex life.
- Your physical ability to give and receive sexual pleasure may change.
- You may suddenly find you don't feel sexually attractive.

Try to remember that many of these changes won't last forever. And you can ask for help when you need it.

Even with these challenges, sex doesn't have to stop completely. At the same time, you need to know that your sex life may not be exactly the same as it was. For example, your favourite lovemaking positions may no longer be comfortable, or intercourse may not be possible for a while.

But if you're willing to try new things, you and your partner can find ways to be close. Trying new things might include oral sex, masturbating on your own or with a partner, or using sex toys like dildos or vibrators.

“ *Maybe try some new stuff ... Throw away your inhibitions ... Open your mind for sure.* ~ Barb*, partner of cancer survivor

After Ian* was treated for prostate cancer, he and his wife Ingrid* came up with a new kind of sex life that didn't include intercourse. They've gone back to activities they used to enjoy, like showering together, cuddling at bedtime, holding hands and kissing before leaving for work. Hobbies, holidays and seeing friends have become more important. “Instead of focusing on this thing that isn't working, we're kind of ignoring that and doing other things and stumbling into happiness through it,” says Ian.

Will sex make the cancer worse?

Having sex will not make cancer worse. Sex doesn't increase the chances of cancer coming back or spreading.

Can having sex give my partner cancer?

If you have cancer, you cannot give it to someone else through kissing, touching or having sex – it's not like a cold or flu.

While you cannot give cancer to your partner if you have it, you should ask your doctor if there are times during your treatment when you should avoid having sex for any reason.

Talking about sex and sexuality

“ *It wasn't easy to talk about. Sexuality. We fumbled about before we eventually got it out on the table.* ~ Ali* and Terry*

You're not alone if you find sex and sexuality hard to talk about. Many people have been raised to think that talking about sex is wrong. Even with your partner, you may feel awkward or embarrassed.

And it can be even harder to talk about the effect cancer has on your sex life. You may feel like withdrawing, hoping to spare your partner from your fears and worries.

“ *There was a time after he had the surgery where it was really difficult because we didn't know if he was going to be able to have a sexual relationship again. And his way of dealing with it was kind of retreating for a while ... And that I found very stressful for me.* ~ Carol*, partner of cancer survivor

Sometimes, it's the partner who avoids talking and withdraws. As one partner put it, “I never bring it up because I know he can't help it. There's nothing he can do about it.”

While you may feel a bit hopeless, there is almost always a way to improve things. And it may seem hard, but talking openly and honestly is the best way to get through any issues you're having in your sex life. Sharing your feelings about sex and sexuality can help you feel closer again, understand what the problems are - and find solutions.

Why it's important to talk with your partner

- Communicating openly about sex is an important part of healthy sexuality.
- Talking can help you make changes to your sexual routines and find new ways to feel pleasure.
- Talking can help you deal with fear and insecurity.
- There are things your partner needs to know, such as where you're feeling pain or what sexual activities you aren't ready for.
- Your partner may also have concerns, such as a fear of hurting you or putting pressure on you.
- Your partner may feel rejected if you don't explain that the cancer or treatment has affected how you feel about sex.

“ *You have to communicate with your partner - otherwise, they can be at a loss in terms of understanding what you are going through.* ~ Marie*

Before her surgery for breast cancer, sex wasn't something Jess* and her husband really talked about. "In the past, everything was fairly effortless. But now, there's things that need to be sorted out," says Jess. She was amazed at how good it felt to talk about "intense topics like feelings about life and treatment and body image. These were things that didn't really come up before and made me feel so close to him."

Cam* and Carol* found that talking to each other *during sex* became more important after his prostate cancer diagnosis. It was awkward at first. But it was the only way to explain what felt good and what didn't. Over time, talking got easier. And it helped them find new ways to be sexually satisfied together.

What do you value about sex?

This may be the most important question you and your partner ask each other. Your answers can help you understand what your sexual relationship means to each of you.

Here are some other questions to help you start talking:

- What do you value most about our sex life - intimacy or physical pleasure? Or something else?
- Is there anything that makes you nervous about working on our sexual relationship?
- What might be hard about trying new things? How should we talk about it if it's not working?

> TIPS on talking to your partner

- Find a time and a place where you won't be interrupted or distracted.
- Practise by writing down your thoughts or saying them out loud.
- Listen to each other and be patient.
- Be clear about sexual problems. If you feel pain or discomfort, say so - and also tell your partner what feels good.
- Try to explain your feelings in a positive way. For example, you might start by saying, "Our sex life is really important to me. Let's talk about what we can do to get back on track."

Dan's story: Communicating with your partner

Dan and his wife had always talked openly about sex. But when Dan was diagnosed with prostate cancer at age 49, they needed to talk more than ever. "There were short-term, mid-range and long-term issues," says Dan. "We talked about them all."

Because Dan was having his prostate removed, one of the topics was his fertility. "We knew we wouldn't be able to have kids after the surgery, and we knew we might want another child," says Dan. The couple decided to go to a fertility clinic, where Dan could bank his sperm before having surgery.

They also needed to talk about side effects like erectile dysfunction (ED). Dan's doctor had explained that they would use a nerve-sparing technique to try to preserve erectile function. But there were no guarantees.

"You need to be able to deal with the worst-case scenarios," says Dan, "to be able to say, 'Here's where we are now sexually, and here's hopefully where we'll get back to. But if we don't, it doesn't mean anything is different between us.'"

After his surgery, Dan needed radiation therapy. With ED and mild incontinence as the main side effects, it was just too early to resume lovemaking.

"Once we realized you can't hurry love, we were okay," says Dan. They found their way forward with intimate activities they'd enjoyed before. "Whether it's just going out or dinner, or candles in a bathroom, or a hot tub – there's so many other things you can focus on because you're alive to focus on them."

With time, things started to improve. The couple discovered the best times for their intimate activities – like earlier in the day when muscles weren't tired and incontinence wasn't a worry. They talked about what worked and what didn't.

As time went on, "Things started to feel different, and response and reaction was different. You just felt healthy again," says Dan, who turned to writing as one way to cope with his experience. About eight months after his surgery, Dan and his wife decided to try in vitro fertilization. It worked the first time. When their daughter was born, Dan proudly announced, "We have our amazing Grace!"

Talking to your healthcare team

Many people find it hard to talk to their doctor about sexual problems. You may find it awkward or feel that the topic is too private. It's true that even doctors can sometimes be embarrassed. This can then make you feel even more uncomfortable – but it's always okay to ask questions about your sexuality. And doctors should be willing to talk about it, just as they would about any other health issue. If your doctor can't help, ask to talk to someone who can.

“ I used to go into my doctor's office, and he would say, 'How are you today?' Now I walk into his office, and the first thing he says is, 'How are your erections?' ~ Dan

If there's someone else you trust on your healthcare team, like a nurse or social worker, it's okay to start the conversation with them. If they can't answer your questions, they should be able to find the answer or refer you to someone who can.

Finding professional help if you need it

Medical doctors who treat sexual problems with medicines call themselves *sexual medicine specialists*. These specialists sometimes work in sexual rehabilitation programs or other organized programs. Some gynecologists, urologists, psychiatrists or family doctors may also be able to help with sexual problems.

Many members of your healthcare team, such as nurses, social workers and psychologists, should be able to give you information, suggestions and support. If they have expertise in sexual issues, they may call themselves *sexual counsellors* or *sex therapists*.

Many treatment centres have specially trained sexual counsellors who help you – on your own, with your partner or even in a group.

Counselling can help you:

- talk openly about your problems
- work through your concerns
- find new ways of experiencing sexual pleasure despite changes to your body

It can be hard to find a sexual counsellor or sexual medicine specialist, especially outside of a big city. But you may be able to get the help you need from other healthcare professionals. For example, a psychotherapist can help you feel better about changes to your body, suggest ways that you and your partner can communicate more clearly and give you skills to cope with cancer and cancer treatment. And many professionals who offer couples or marital counselling are also familiar with sexual concerns.

It's important – but worth it – to keep trying until you find the person who can give you the help you need.

“ *You have to start thinking in a totally different way. You've got to be almost that hypochondriac that you always talked about – but you're not. You just have to be able to discuss everything that's involved.* ~ Dan

Questions to ask your healthcare team

Many people find it helpful to write a list of questions and add to it as they think of new ones. Just writing down a question can make you feel that you're doing something about it. These questions can get you started.

- Will this treatment affect me sexually?
- Will this treatment affect my hormones?
- Will the changes be permanent?
- When will I feel like having sex again? When is it safe to have sex again?
- How soon can I masturbate or have sex?
- What sort of problems could we have during intercourse?
- It hurt when we had intercourse. Why?
- What kind of birth control should I use?
- Is there anything else I should do to protect myself or my partner?
- Will I be able to have children after treatment?
- If I've had a sexually transmitted disease or infection, will it come back with cancer treatment?
- Will I ever feel normal again?
- Where can I get more information or find a sexual counsellor or sex therapist?

If you are lesbian, gay, bisexual or transgender

If you're lesbian, gay, bisexual or transgender, it may be extra hard for you to talk about sex with your healthcare team. You may not want to be open about your sexual orientation, or you may fear prejudice.

“When you are gay, it might be hard in a small community to be open with your doctor, but I've also heard people say, 'You'd be surprised at the positive reaction.' ~ Paul

> TIPS

- Find healthcare professionals who are sensitive to gay and lesbian issues. Look for rainbow triangle stickers in offices. Listen for inclusive language such as the use of the word “partner”.

“I told my doctor, 'I'm a gay man and single, and maintaining my sexuality is very important to me.' She was very comfortable with that. ~ Paul

- Talk to a trusted nurse or social worker first if you're not sure about telling your doctor.
- Surround yourself with supportive friends and family members.

“I needed the consistent support to outshine the negative thoughts I had that maybe I got cancer because I'm gay. ~ Dana*

Dana's story: Cancer, sexual orientation and telling your doctor

When Dana* faced a cancer diagnosis, she'd been “out” for a while and was okay with telling her healthcare team. “They need to understand who your support system is and the dynamics going on in your life,” she says.

As every cancer patient knows, there are many healthcare professionals involved in cancer care – so Dana had to disclose her sexual orientation over and over again.

“As a gay person, I've learned how to send out cues and clues in my conversations to see how comfortable healthcare providers are with these issues,” she says. “I pay attention to whether a doctor uses the word ‘partner’ and other inclusive language.”

There were frustrating moments with some who didn't get it and “assumed that I was straight”. But Dana feels that more and more healthcare professionals now understand the issues lesbian, gay, bisexual and transgender (LGBT) cancer patients face.

“There is support out there, and you are not alone,” she says.

An important support person for Dana was the social worker at the local cancer centre. “I could go in there and let everything out in a non-biased environment. I could be open about the dynamics of my relationship, which was very strained. I had a partner at the time who was not out, and that was making it difficult for her to support me fully through the cancer journey.”

Family and friends were also important supports for Dana. “I'm blessed that I had, and continue to have, a strong support system. Some LGBT people do not, and cancer for them becomes an additional strain or cause of further estrangement.”

Your body and how it works



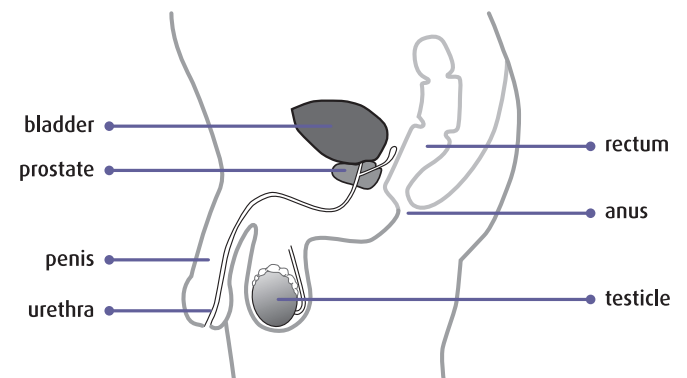
“ If I hadn't asked my doctor about the problems I was having during intercourse, I would have just let sex go. Instead, he came up with a solution that worked. ~ Marie*

Sex organs in men

A man's sex organs (or genitals) are mostly outside his body. The end of the penis is covered by the foreskin, if it hasn't been removed by circumcision. The urethra, where semen and urine pass out of the body, opens at the end of the penis. The testicles are contained in the scrotum, which lies below the base of the penis. The testicles make sperm and store it. They also produce the male sex hormone, testosterone.

The prostate is deep in the pelvis, inside a man's body, surrounding the urethra as it leaves the bladder. It makes part of the liquid (seminal fluid) that mixes with sperm from the testicles to make semen.

In addition to the penis, the chest and nipples can also be sexually sensitive. Men may have other highly pleasurable (or erogenous) zones such as the nape of the neck, back of the knees, buttocks and inner thighs.

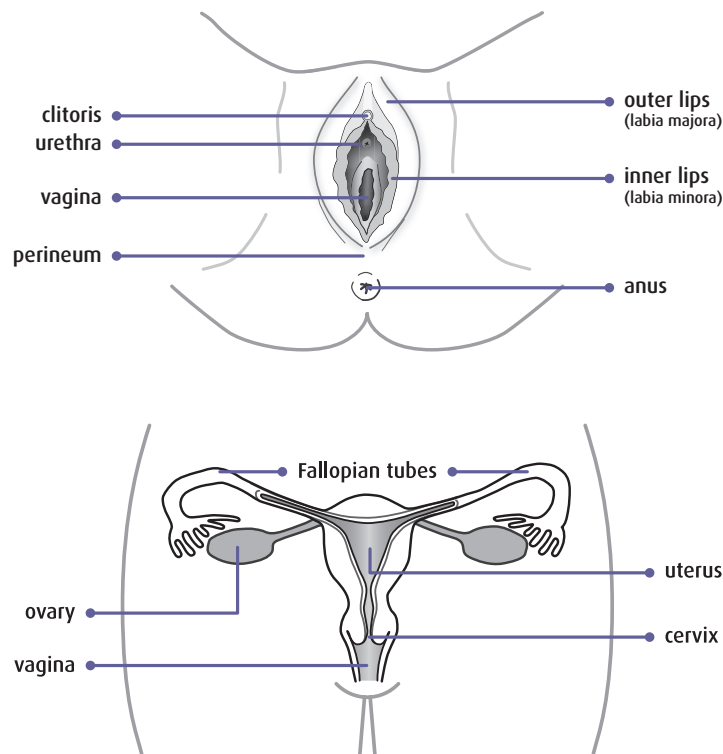


Sex organs in women

The uterus (womb), the cervix (neck of the uterus) and the ovaries are inside a woman's body.

The sex organs outside the body (or genitals) are called the vulva. These include the outer lips, or labia majora. When parted, these reveal the thinner inner lips, or labia minora. These join at the top to cover the clitoris with a fatty hood. The urethra, for passing urine, is between the inner lips and behind the clitoris. Further back is the vagina. Beyond that is an area of skin called the perineum and beyond that is the anus.

While the vulva, especially the clitoris, are the most sexually sensitive parts of a woman's body, other pleasurable (or erogenous) zones of a woman's body include the breasts and nipples, the nape of the neck, back of the knees, buttocks and inner thighs.



Your brain is a sex organ

It may sound strange, but the most important sex organ for both men and women is the brain. It is with our brains that we:

- experience sexual thoughts and fantasies
- interpret touch as sexual
- interpret touch as pleasurable or not
- experience ourselves as sexual beings (or not)

In response, the brain sends signals to your sex organs causing the signs and feelings of arousal. The brain is also important because it manages the production of the hormones testosterone, estrogen and progesterone. These hormones are important for various aspects of sex, sexuality and sexual function.

The sexual response cycle

The phases of the sexual response cycle are desire, excitement, orgasm and resolution.

Desire is your interest in sex or sexual appetite. (It is sometimes called *libido*.)

Excitement is when you feel “turned on” or aroused. Your heart rate and blood pressure go up, you may feel warmer and breathe heavier and blood is sent to the genitals. In both men and women, the nipples may harden and erogenous zones become more sensitive to touch. Sexual tension builds throughout the body. In men, the penis becomes erect and sensitive to touch. In women, the vagina becomes moist and increases in depth and width.

Orgasm is the peak of sexual response when the sexual tension that was built up in the excitement phase is released. The nervous system generates intense pleasure in the genitals. Muscles around the genitals contract in rhythm, sending feelings of pleasure through your body. In men, these muscle contractions cause the release (ejaculation) of semen.

Men usually cannot be sexually aroused again for a while.
Some women are able to have multiple orgasms.

Resolution is when your body returns to its normal state.

Not all experts agree that everyone follows this set pattern of sexual response. Many experts think that women (and some men) may not always feel sexual desire at the start of a wanted sexual experience. They may be looking mainly for emotional closeness at first and the sexual desire comes after.

Cancer and the response cycle

Cancer and its treatment can affect any stage of the sexual response cycle. For example, your desire for sex could change if you have hormonal therapy or if pain during sex is a side effect of your treatment. Some treatments may slow down your body's ability to respond during the excitement phase or affect your ability to orgasm. While these changes are challenging, they may be temporary.

Even when cancer changes your regular sexual routines and your sex life becomes very different, you can still feel sexual pleasure. For example, nerve damage after surgery may stop a man from getting erections, but he can almost always feel pleasure from being touched. In fact, he can still reach orgasm even if he doesn't have an erection. This is because the nerves that allow a man to feel pleasure when the penis is stimulated are separate and follow a different path from nerves that control blood flow.

“ *Before my treatment, I didn't know that you could orgasm without an erection. Even though there's no sperm, there are still the muscular responses, and your brain is still 17!* ~ Dan

Sex and relationships during and after cancer treatment



“ It would be nice if we could go back to the pre-cancer days, but we can't, so that's the reality. ~ Carol*

Reacting to a diagnosis

If you've just been diagnosed with cancer, you're probably busy learning about it and making decisions about treatment. Sex might not seem to matter much because going through treatment takes over your life for a while. Some people don't think about sexual relationships until after treatment is over, and they begin to focus on the “new normal” of life after cancer.

“ I think there's a pretty big preoccupation with 'Holy crap! I've got cancer!' That's front and centre ... it is a period of survival. ~ Ian*

Or you might find that sex is just as important as it was before the cancer diagnosis. For some people, sex can even become *more* important during a cancer experience.

“ Being intimate with a supportive partner can be the most affirming experience. ~ Dana*

After her mastectomy, Jess* found there were times when she wanted to have sex with her husband and other times when she only wanted to cuddle in bed. “There's so much comfort to be had in being held or just being in bed together,” she says.

If your partner has cancer, it's normal to have mixed feelings about sex. Says one partner of her husband's cancer diagnosis, “I felt guilty. People would say, ‘Well you've got your husband, these things aren't important, just put that aside, don't worry about it anymore.’ Well, I still had all the feelings. I still had the libido.”

All of these reactions are normal.

Changing roles and relationships

Roles and relationships in your life may change during your cancer experience. These changes can affect your sexuality and sexual relationships in ways that are both positive and negative.

For example, if treatment makes you too tired to do your usual household tasks, it may affect your role in the family. Or you may be off work during treatment and not able to provide for your family in the way you used to. Either situation can make you feel helpless, as if you've lost control over your life, and can affect your feelings about your sexuality and sexual relationships.

A cancer diagnosis can make you feel cheated, like something has been taken away from you. You and your partner may have made plans for the future that have to change now that you have cancer. You may have been looking forward to having children or to children leaving home, allowing you more freedom and time for each other.

Even with these challenges, keep working on your sexual relationship, whatever it becomes.

“ *It's important to grieve the past and move on to a "new normal" in sexual relationships as well as in the marriage as a whole.* ~ Louise*, partner of cancer survivor

Sexual experiences can help couples stay connected and give both partners a needed release from stress. Some couples say that sex helps to make up for other problems in a relationship.

Different levels of sexual desire

Sometimes one partner is more interested in sex than the other. This can be a challenge for any couple. While you may have learned to live with these differences in the past, cancer can add to the problem.

“ *He's just out of surgery and he wants to have sex. You know? He still has his staples and he wants to have sex. And I'm like, can we recover first?* ~ Juanita*, partner of cancer survivor

Sometimes a cancer diagnosis can balance a mismatch in sexual desire.

“ *The imbalance was before, where he was always more active than I was, so he'd be ready, he'd be aroused, he'd want to have sex and sometimes for me, it didn't matter. He'd have to arouse me to get me into his mood. But now, we seem to be at the same level.* ~ Anne* and Peter*

If you're dealing with mismatched desires, you and your partner need to talk openly and honestly. Together, you can decide on ways to satisfy each other sexually, with or without intercourse. You can also try videos or sex toys like dildos and vibrators for yourself or for mutual pleasure.

New levels of intimacy

“ *Sex is even more meaningful and pleasurable after going through cancer, if you are with someone you care about.* ~ Marie*

Some couples find a new level of intimacy, understanding and love for one another when facing a shared challenge like cancer.

“ *We probably had some of the closest times with the increased vulnerability that he has allowed himself to have ... He's more responsive than he's probably ever been in all these years.* ~ Carmen* and Gerard*

How cancer affects your sexual relationship may depend on how strong the relationship was before. A strong, loving relationship is more likely to survive the stresses of cancer. A relationship that is struggling probably won't improve after diagnosis.

“ *Cancer can highlight and heighten dysfunction in relationships like nobody's business. And that's what happened to me in my relationship at the time.* ~ Dana*

Sex and advanced cancer

People approaching the end of life can still have sexual feelings, even if they're in too much discomfort to think about enjoying sex. The need for intimacy – whether it's a caress or something more – can be just as important as before. In fact, the need for affection may become stronger.

If you have advanced cancer, your needs can be hard for partners to understand, especially if they are also your caregivers. Physical intimacy has probably changed as the cancer progressed. Your partner may be worried about hurting you and unable to enjoy the experience because of these feelings.

Try to talk openly about how you're both feeling. Simple pleasures such as kissing, touching and holding one another, or just spending quiet time together, can be healing for you – and for your relationship.

Paul's story: A gay man's perspective

Paul was working hard as a flight attendant when he was diagnosed with prostate cancer in 1996. Radiation therapy didn't keep him grounded for long. "I kept the flying going because the flying kept me going," he says.

But the treatment took a toll on Paul's sex life. Erections were no longer a sure thing. As a single gay man, it was "very frustrating," he says. Paul knew he could still experience pleasure without penetration or orgasm – but how would a partner feel?

"For a gay man, to see another man with an erection is exciting. Penetration can sometimes be important. The sight of another man ejaculating can also be a turn-on. Now, I couldn't even do that – or very seldom."

Paul was open with partners about what might – and what might not – happen when they had sex. He had a relationship with one man who "didn't care in the least." "We had great encounters because it was more personal. We were enjoying each other's company, whether or not there was an erection. It took the pressure off me, and then I could maintain an erection."

In 2004, Paul needed photodynamic therapy, which brought a new sexual side effect – a decrease in sex drive. Then, in early 2007, he began hormonal therapy. Now there were no erections and no desire. At the same time, Paul turned 65 and had to retire from a career he loved. This "double whammy" resulted in depression. He saw a psychiatrist for over a year and surrounded himself with friends.

Paul had always talked openly with his healthcare team about everything. But it was at a group for gay men with cancer that Paul was able to "really open up about my sexual dysfunction because I wasn't the only one."

After three years of hormonal therapy, Paul was able to stop taking the drugs for 15 months. He experienced "stirrings", waking up with semi-erections. Now back on hormonal therapy, he hopes to get another therapy vacation – and to get things going again.

Keeping your sex life going

“ *Life has changed, so do things differently. You are going to have to adapt ... Experiment, but don't do it individually, do it together. If you share it, it will bring you together.* ~ Mark*

There are many things you and your partner can do to keep or rebuild a healthy sex life during or after cancer treatment. It might seem hard at first, but you can learn to adapt.

Get information

Eric* was dealing with erectile dysfunction after treatment for prostate cancer. It wasn't easy getting the information and help he needed. He tried oral medication, a pump and injections to have intercourse. His partner, Emily*, felt that it was only because of Eric's determination to search for information and to keep trying that they were able to bring back his erections.

It's okay to be like Eric - to ask many questions and to keep asking them until you get the answers you need.

When starting your own research, ask someone on your healthcare team about pamphlets, books, videos and online resources from trustworthy organizations.

What to avoid

You may be very upset by sexual problems during your cancer journey - so upset that you might be tempted to get advice from people who aren't qualified healthcare professionals and who offer you unproven treatments or remedies for your problems. There are lots of ads for these "treatments" of unproven creams, pills, supplements, aids and devices online and in free newspapers and magazines.

These therapies can be harmful and interact with the treatments planned by your healthcare team. Be sure to talk to your healthcare team before trying any of these remedies or products.

Share information, feelings and concerns

“ *We've always been very open with one another. And this just became one of the other things we deal with.* ~ Dan

You're not alone if you envy Dan and his ability to be so open. For some couples, sex is the hardest topic to talk about, no matter how well they know each other and no matter how long they've been together. But you need to try. Couples who talk openly have more satisfying sexual relationships. They trust each other to cope with their thoughts and feelings.

When talking through issues, try to avoid blaming anyone. You're both coping with a lot of change, and the goal is to discover how to move forward in a way that works for both of you.

Your partner can't know what you need unless you talk about it. For example, tell your partner if they need to touch you more. If you feel weak, sore, tender or tired, guide your partner to areas that feel good.

Go slowly

You may feel anxious or afraid about your first sexual experience after cancer treatment. These feelings may make you avoid getting close to your partner. Your partner may also be afraid to suggest sex, thinking that it might hurt you. Go slowly and take it one step at a time. Start with lots of closeness, hugging and other things that you feel comfortable with.

“ *Things will happen when they happen. In our case, we were just trying to have intercourse too soon.* ~ Dan

Be patient, be hopeful and keep trying

When old ways of having sex don't work anymore, it can take time to accept this and create a new sexual range. You'll need to experiment, refine and communicate a lot as you find out what feels good and what doesn't.

Set the mood

Plan a romantic date. Set the mood with soft lighting, candles and music. Have an intimate dinner for two. Focus on the sensual – give each other massages, have a bath together, wear sexy lingerie or clothing if it makes you feel good.

Make a plan

For many people, sex is all about being spontaneous. But if you have sexual problems because of cancer and its treatment, making a plan can help. For example, one couple used injections to help with erectile dysfunction. They scheduled one day a week for sex and followed a routine:

“ *We'd have a long leisurely breakfast, he would go and inject, we would make love and then go out for lunch. So the whole day, we would try to set aside for ourselves, just to be a couple together.* ~ Carmen* and Gerard*

And, of course, it's not all about sex. Plan other activities with your partner – whether they lead to sex or not. Go for a walk in the park or see a movie. Do things that you enjoy as a couple so you're not focusing on sex or cancer all the time.

“ *We like having nice dinners, we like having a nice bottle of wine, we like going out, having a game of golf. I still like to somehow get involved, sexually involved, even though it doesn't involve intercourse.* ~ Anne* and Peter*

Be open to new ideas

“ *There's so many different things you can do to have intimacy, whether it's just a touch in a different way, or sharing a fantasy, or somebody taking it one step further than before.* ~ Dan

For some people, the sexual changes that come with cancer and treatment may be permanent. Or there may be times when sexual intercourse isn't possible. This may upset you or make you angry, but it can also be a chance to learn new ways of giving and

receiving sexual pleasure. It doesn't mean that you can no longer have a sexual relationship with your partner – but it's important to understand and accept that you'll need to change how you have sex. Only then can you move forward and discover other ways to feel sexual pleasure.

Try something new, whether it's finding areas that give you pleasure through masturbation, manually stimulating each other or experimenting with oral sex or sex toys. Hug, kiss, caress and be naked together. If sexual intercourse is possible, try different positions to find the ones that are most comfortable and pleasurable.

“ *We started reading stories to get ideas and, lately, going online. I used to feel really uncomfortable about watching pornography but now I kind of like it.* ~ Jess*

And don't forget to keep your sense of humour!

Cancer may not be funny, but a sense of humour can help you cope with it. Laughing is a great way to deal with intense feelings and to keep things in perspective.

“ *We laugh a lot more when we make love than we ever did before. I think that's actually added a huge dimension to our lovemaking.* ~ Carmen* and Gerard*

Lovemaking has many benefits for you and your partner

- It offers a way to be close, connected and intimate with your partner.
- It gives you and your partner pleasure and relieves stress.
- It reassures you and your partner that you still love each other and find one another attractive.
- It distracts you from the challenges of cancer and helps you feel safe and secure.
- It increases your circulation and strengthens and relaxes your muscles.
- It can help you sleep.

“If the emotional closeness is retained through sex or intimacy, it strengthens a couple to carry on with other aspects of life with more ease and naturalness and humour.” ~ Louise, partner of cancer survivor*

If you're single

If you're single, family and friends may play a bigger role than ever in supporting you.

“ I've surrounded myself with lots of friends. And the majority are all gay couples who've known me for 15 or 20 years. I think I'm privileged that I have so many close friends. ~ Paul

You may worry about how a new partner will react to the news that you've had cancer or wonder when you should talk about it for the first time. There's no timeline for this, but relationships that last are based on honesty – so when a new relationship is getting serious, it might be time to say something.

“ I've always been very open about my cancer. That's how I heal from it. I know a lot of people heal by being able to leave it in the past. I kind of embrace it. ~ Dana*

You may be pleasantly surprised by the response you get. It's important to find a partner who accepts you as you are. Your relationship will be more solid if it's based on openness and honesty. So make the time to talk about your cancer experience.

And if the response isn't good, then at least you've learned that this person isn't right for you. Remember that rejection can happen to anyone – whether they've had cancer or not. And keeping to yourself just to avoid rejection means you will never have the chance to have all the good things that go along with a great relationship.

> TIPS

- Plan or practise the conversation with a counsellor or friend.
- Keep your comments simple. Don't overwhelm your partner with details.
- Start “the cancer talk” in a relaxed atmosphere, when you and your partner are feeling close to each other.

Marie's story: Life as a single woman after cancer

Marie*, a healthcare worker, was 45 when she had a mastectomy and chemotherapy for breast cancer. About a year after finishing chemo, she joined a singles group and started dating.

It was usually after a second date that she mentioned her cancer experience.

“I would tell them that I am a breast cancer survivor and explain that I had a prosthesis,” says Marie. “Most men were very good about it and didn't make me feel self-conscious. If you are with a mature man, it's not an issue.”

But there were exceptions. Marie was amazed when one man asked her if the cancer was contagious. “That one didn't last very long!” she laughs. Others would ask, “Are you sure the cancer is over and done with?”

Says Marie, “Many men, at that age, aren't exposed to women with breast cancer.”

In her fifties now, Marie has discovered that many of her dates are often dealing with medical challenges of their own. She isn't the only one with something to share.

“The older you get, the more medical issues people have anyway. You find out that you are dating someone who has high blood pressure or diabetes or they are on antidepressants.”

She's also found a way to meet people that takes the pressure off – the Internet. “It's a good place to start because the topic of health and cancer treatment doesn't have to come out for a while. You don't have to tell your whole life story.”

A year ago, Marie's eyes were drawn to one man's online profile. There was no photo but, “I really liked what was written in it.” They started seeing each other. After a few dates, Marie was surprised when he raised the topic of cancer. “And he told me that he is a prostate cancer survivor,” she says.

Today, the two are closer than ever. “He's someone I can be honest and comfortable with. Life is good now, and I'm going to enjoy it as much as I can.”

Choosing not to have sex

“ *I’m fine with it. To me it’s not a priority in my life now ... It isn’t necessarily high on the list. Yes, it’s nice to have, but it’s not a must-have. It might be a want, not a need.*
~ Robert* and Sacha*

When you have cancer, you may decide not to have sex for a while. Healthy self-esteem is about being true to yourself – and this is your choice to make.

Even if you don’t want a sexual relationship, remember that we all need physical affection to thrive. If sex is not for you right now, you can still wrap your arms around your partner or share a hug with family or friends.

Cancer treatments and sexual function



“ My doctors didn't raise the topic of sexuality and side effects. That's not to say I was badly treated by my doctors. But you have to be willing to take the initiative. ~ Mark*

Safety and pregnancy during cancer treatment

Is it safe to have intercourse during cancer treatment?

Ask your doctor if sexual activity may be a problem during or after treatment. You need to know what safety measures, if any, to take. For example:

- Some chemotherapy drugs can get into vaginal fluids or semen. Your doctor can tell you about how to protect your partner if you have sex during a chemo cycle.
- Men who have radioactive implants (or seeds) to treat prostate cancer should wear a condom during sex until their doctor says it's safe to not wear one. The seeds shouldn't be touched, so if one shows up in semen or urine, use tweezers or a spoon to pick it up and flush it down the toilet. (Flush twice, just to make sure it's gone.)

Depending on your treatment, it may take some time or you may need medical help before you can have penetrative intercourse. For example, doctors often suggest that women avoid vaginal intercourse very soon after surgery or radiation to the pelvic area.

How does pregnancy affect a treatment plan?

It's best to avoid getting pregnant while you're being treated for cancer. If you think you'd like to have a child in the future, talk to your team *before* you start treatment. All types of treatment can affect your fertility (the ability to get pregnant or father a child).

If you're pregnant when you're diagnosed with cancer, your healthcare team will plan the best treatment they can for you while also considering the possible risks to the unborn baby.

Surgery generally has the least risk to the baby, especially after the first trimester.

Some chemotherapy drugs can be given during the second and third trimesters without harming the baby. This is because the placenta acts as a protective barrier between the mother and baby. (The risk is that the drugs could cause early labour and low birth weight.)

Unborn babies can sometimes be protected by special shields during radiation therapy. You may also be able to wait to start treatment until after the 12th week of pregnancy, when it is less likely to cause harm.

This chapter describes the most common types of cancer treatments and how they might affect your sex life. Tips on dealing with the symptoms and side effects are in the next chapter.

Surgery

Surgery is a medical procedure to remove or repair tissue. Many different types of surgery are used to treat cancer, and the type of surgery you have depends on the size of the tumour and where it is.

Surgery and your sex life

The physical and emotional effects of *any* type of surgery can affect your sex life, whether the surgery is on a sex organ or another part of your body. Many of the side effects of surgery are short-term changes, but some can become long-term challenges.

The main types of surgery used to treat cancer, and how they may affect your sex life, are outlined below in alphabetical order.

Abdominoperineal resection

Abdominoperineal resection is surgery to remove the lower colon, rectum and anus. During this surgery, the surgeon creates a stoma (artificial opening) in the abdominal wall that allows stool to leave your body. This procedure is called a colostomy. A special bag or pouch (colostomy bag) is attached to the stoma to collect food waste from the colon.

It will still be possible for you to have an enjoyable sex life while living with a stoma – it just may take some adjustment and planning.

In women, sex organs are sometimes removed during this surgery. This may include removing the uterus and ovaries, which can affect sexuality and fertility. The rear wall of the vagina may also be removed. The remaining vaginal tube is then repaired using skin grafts, muscle flaps or both.

Many women have an enjoyable sex life after an abdominoperineal resection, but you may need to use lubricant and try different positions to find what works best for you.

*If your uterus is removed as part of your surgery, see **Hysterectomy** on page 42.*

*If your ovaries are removed as part of your surgery, see **Oophorectomy** on page 43.*

Amputation

Amputation is an operation to remove all or part of a limb. Improvements in surgery and other treatments have made it possible for doctors to remove only the affected part of the limb so that they rarely need to amputate an entire arm or leg.

Artificial arms or legs (prostheses) often replace ones that have been removed. Although having a prosthesis may make you self-conscious, you can still have a fulfilling sex life. Some people have sex wearing their prosthesis and find that it helps with positioning and movement. Others find that the straps used to secure the prosthesis are uncomfortable and get in the way.

Some people experience phantom pain after amputation. This is pain or changes in sensation that seem to come from the part of the body that has been removed. Any type of pain can be distracting during sex and may reduce sexual desire. Phantom pain usually goes away in time, but it can be a long-term problem for some people.

Breast-conserving surgery (lumpectomy) and mastectomy

There are two main types of surgery for breast cancer – breast-conserving surgery (lumpectomy) and mastectomy. The type of surgery you have depends on the size of the tumour, where it is and if any lymph nodes are involved. How your breast looks after surgery will depend on where the tumour was and how much breast tissue was removed. Breast reconstruction may be possible.

In breast-conserving surgery, the tumour, some of the tissue around it and possibly some lymph nodes are removed.

A mastectomy removes the entire breast, including the nipple. Different types of mastectomy remove different amounts of surrounding tissues.

A total mastectomy removes the entire breast, but the lymph nodes and muscle under the breast are left in place. A modified radical mastectomy removes the entire breast and some of the lymph nodes in the armpit. The muscle under the breast is left in place.

A radical mastectomy removes the entire breast, some of the lymph nodes in the armpit and the muscle under the breast. This type of surgery is seldom done any more.

Breast cancer surgery shouldn't affect your ability to feel sexual pleasure or reach orgasm, but it may affect your self-esteem and desire for sex. Some women like to be stroked around the areas of the healed scar, while others don't enjoy being touched in the affected area.

Cystectomy

Cystectomy is surgery to remove part or all of the bladder. The type of surgery you have depends on the size of the tumour, where it is and if any lymph nodes are involved.

A partial cystectomy removes the tumour and a part of the bladder around it. This type of surgery usually doesn't cause sexual side effects.

Radical cystectomy removes the entire bladder. During this type of surgery, surrounding tissues, lymph nodes and nearby organs are also removed. When the entire bladder is removed, the surgeon either makes an artificial bladder to store urine inside the body or creates an opening (stoma) in the abdominal wall so the urine can pass out of the body, where it's collected in a bag (or pouch). The operation to make the stoma is called a urostomy. After surgery, it may be hard to control your bladder (incontinence), but this usually gets better over time.

It's still possible for you to have an enjoyable sex life while living with a stoma – it just may take some adjustment and planning.

Radical cystectomy may involve the removal of sex organs, which affects women and men in different ways.

In women, the uterus, cervix, Fallopian tubes, ovaries, front wall of the vagina and urethra are removed in a radical cystectomy. Removing the uterus or ovaries can affect your sexuality and fertility.

*If your uterus is removed as part of your surgery, see **Hysterectomy** on page 42.*

*If your ovaries are removed as part of your surgery, see **Oophorectomy** on page 43.*

In men, the prostate, seminal vesicles and part of the urethra are removed in a radical cystectomy. Removing the prostate and seminal vesicles can affect your sexuality and fertility.

*If your prostate is removed as part of your surgery, see **Prostatectomy** on page 45.*

Facial surgery

Surgery for head and neck cancers sometimes leaves scars and may affect you in other ways. For example, surgery that involves the jaw or tongue may change the way you speak. Head and neck surgeries can also affect intimacy as they may change the way you kiss or have oral sex.

Changes to your appearance can affect how you feel about yourself and may lead to low self-esteem. Plastic surgery may make you more confident of your appearance and improve your ability to speak.

Hysterectomy

Hysterectomy is surgery to remove the uterus. The cervix and ovaries may also be removed during a hysterectomy. The type of surgery you have depends on the size of the tumour, where it is and if any lymph nodes are involved.

A partial hysterectomy removes the upper part of the uterus, but not the cervix or other organs. A total hysterectomy removes the uterus and the cervix. During a radical hysterectomy, the surgeon removes the uterus, cervix, upper part of the vagina next to the cervix, some of the surrounding tissues and nearby lymph nodes in the pelvis. In some cases, the ovaries are also removed. After removing the cervix, the surgeon stitches the vagina at its top.

The different types of hysterectomy can affect a woman's sexuality and fertility in different ways. If your uterus is removed, you won't be able to get pregnant and your periods stop. But you can still feel sexual pleasure. The area around the clitoris and lining of the vagina generally stay as sensitive as before. Orgasms almost always return. If the cervix is removed and the vagina is stitched at the top, the vagina may be shorter. Spending more time on foreplay usually helps during sex because the vagina has more time to lengthen.

*If your ovaries are removed as part of your surgery, see **Oophorectomy** on page 43.*

Laryngectomy

Laryngectomy is surgery to remove part or all of the voice box (larynx). When the entire voice box is removed in a total laryngectomy, the surgeon creates a permanent opening in the throat for breathing and talking. The opening is called a stoma.

Improvements in plastic surgery mean that a person's appearance isn't affected as much as it used to be, but having a stoma that others can see may still affect your self-esteem and sexuality.

After a laryngectomy, changes in your speech may affect intimacy and make communication with a partner challenging because it can be harder to express your feelings and emotions. If you need to talk with the help of a special valve or using esophageal speech, this will take much more effort than before, and the volume and tone of your voice will be different.

Oophorectomy

Oophorectomy is surgery to remove one or both ovaries. If both ovaries are removed, it's called a bilateral oophorectomy.

Your ovaries produce most of your body's estrogen, which is important to fertility. If your ovaries are removed, your body can't release eggs to be fertilized by sperm. For young women with early-stage ovarian cancer, it may be possible to remove only one ovary, one Fallopian tube and the omentum (the fatty covering inside the abdomen). This is called fertility-sparing surgery because a woman can still get pregnant with one ovary. If both ovaries are removed, you will go into early menopause, your periods will stop and you won't be able to get pregnant. Symptoms of menopause such as vaginal dryness or vaginal narrowing can make intercourse uncomfortable.

Orchiectomy

Orchiectomy is surgery to remove one or both testicles and spermatic cord.

Losing one testicle won't make you infertile or affect your ability to have an erection. It may affect how you feel about your appearance, because the scrotum will look and feel empty. A false testicle (prosthesis) can usually be placed in the scrotum so that it's not obvious that the testicle was removed.

If both testicles are removed, you won't be able to father a child because your body can no longer make sperm. You can still have sex, as long as you're getting enough testosterone through supplements.

If your surgery involves removing lymph nodes at the back of your abdomen, there is a chance that the nerves that control ejaculations may be damaged. This can cause infertility, so you may want to ask your doctor about nerve-sparing surgery and fertility options such as sperm storage before surgery.

Pelvic exenteration

Exenteration is a surgical procedure to remove all of the organs from a body cavity.

Total pelvic exenteration is the most extensive pelvic surgery – the lower colon, rectum and bladder are removed, along with the sex organs. Removing the lower colon and rectum, as well as the bladder, can affect sexuality.

*For information on removing the colon and rectum, see **Abdominoperineal resection** on page 38.*

*For information on removing the bladder, see **Cystectomy** on page 41.*

Removing the sex organs affects women and men in different ways.

In women, total pelvic exenteration also includes removal of the uterus, cervix, ovaries, Fallopian tubes, vagina and urethra.

*For information on removing the uterus, see **Hysterectomy** on page 42.*

*For information on removing the ovaries, see **Oophorectomy** on page 43.*

In men, total pelvic exenteration also includes removal of the prostate and seminal vesicles.

*For information on removing the prostate, see **Prostatectomy** below.*

Penectomy

Penectomy is surgery to remove part or all of the penis. The type of surgery you have depends on the size of the tumour and where it is.

A partial penectomy removes only a portion of the penis. The surgeon removes as little of the penis as possible, and it's sometimes possible to reconstruct part of it. Many men can still have satisfying intercourse after a partial penectomy. With arousal, the remaining shaft of the penis gains enough length and becomes firm enough for penetration. Although the sensitive glans (the "head" of the penis) is gone, you should be able to reach orgasm and ejaculate normally.

After a total penectomy to remove the entire penis, many men can still reach orgasm when sensitive areas, such as the scrotum, the skin behind the scrotum, the area around the surgical scars or areas inside the anus, are stroked.

Prostatectomy

Prostatectomy is surgery to remove the prostate. A radical prostatectomy removes all of the prostate and the seminal vesicles and some surrounding tissues, including the pelvic lymph nodes. This surgery can affect a man's sexuality in several ways.

When the prostate and seminal vesicles are removed, your body doesn't produce semen, which means you won't be able to father a child. You can still orgasm - but they will be "dry" orgasms because there is little or no ejaculate. Most men find that dry orgasms feel different but are still pleasurable. After radical prostatectomy, you may have some trouble controlling your bladder (incontinence) and may urinate during orgasm (climacturia). This usually gets better over time.

The nerves responsible for erections run in two bundles on either side of the prostate. During a radical prostatectomy, these nerves may be damaged or removed. After surgery, you may not be able to get an erection or keep it firm enough to have sexual intercourse (erectile dysfunction, or ED).

Nerve-sparing radical prostatectomy preserves the nerve bundles and greatly reduces the chances of ED. The surgeon can only decide to spare the nerves once the prostate and the tumour are seen during surgery. If cancer has grown into or around the nerves, your surgeon will not be able to save them.

Even if these nerves are damaged during surgery, most men can still reach orgasm. This is because the nerves responsible for pleasurable feelings in the penis are different from those responsible for erections and are not affected by surgery to remove the prostate.

Vulvectomy

Vulvectomy is surgery to remove all or part of the vulva. The type of surgery you have depends on the size of the tumour, where it is and if any lymph nodes are involved.

A partial vulvectomy removes only the tumour and some normal tissue around it. A modified radical vulvectomy removes the affected area and some normal tissue, along with some lymph nodes in the groin area. The clitoris may also need to be removed.

A radical vulvectomy removes the entire vulva, including the inner and outer lips and the clitoris, as well as surrounding lymph nodes. Radical vulvectomy is very rare.

It's still possible to feel sexual pleasure after a vulvectomy, but you may have problems reaching orgasm after this surgery. The area around the vagina will look very different, which may affect how you feel about yourself sexually. Reconstructive surgery may be an option, although the feeling (sensation) may be different.

If the lymph nodes in the groin are removed, lymph fluid can build up in the area. This swelling, called lymphedema, may make the area sore or affect the nerves, which may then affect sexual pleasure.

Radiation therapy

Radiation therapy uses radiation to destroy cancer cells. During radiation therapy, both cancer cells (which are growing in an uncontrolled way) and healthy cells are damaged. It is this damage to healthy cells that causes side effects, which usually go away as the healthy cells repair themselves.

Radiation therapy can be:

- External - a large machine directs radiation at the tumour and to some tissue around it.
- Internal - the radiation is delivered directly to the tumour or into a body cavity or passage using a temporary or permanent implant.

Sexual side effects from radiation therapy are different for each person, and some side effects depend on the part of the body being treated. Side effects may last for weeks or months after treatment before they go away. Some can be permanent.

Radiation therapy and your sex life

Radiation therapy to any area of your body can cause side effects such as fatigue, skin reactions or changes to sleeping patterns. These common side effects of radiation therapy can affect your sex life.

Bladder and bowel problems related to radiation therapy to the pelvic area may also affect your sexuality.

For women, radiation therapy to the pelvis can damage your ovaries and reduce the amount of hormones they produce. This can affect your interest in sex. You may find that your menstrual periods become irregular or stop during treatment. This can bring on symptoms of menopause, such as hot flashes, vaginal dryness or vaginal narrowing. Some of these changes can make intercourse uncomfortable.

For men, radiation therapy to the pelvic area can cause long-lasting damage to nerves and blood vessels in the penis. Many men will have some degree of erectile dysfunction following radiation therapy. Some men experience dry orgasms – they have erections and reach orgasm but do not release semen. Radiation therapy to the pelvic area can also affect how your testicles function, which may mean you lose some interest in sex.

Some men who've recently had radiation therapy to the pelvic area feel a sharp pain when they ejaculate. This is due to irritation of the urethra. The pain usually goes away within a few weeks.

For both men and women, radiation to the pelvis can lead to infertility – you may not be able to father a child or get pregnant. In men, radiation to the pelvis may affect the testicles so they produce only a small number of sperm or unhealthy sperm. This may affect the sperm's ability to reach and fertilize a woman's egg. In women, radiation to the pelvis can make your ovaries stop releasing eggs.

Radiation therapy to other areas of the body doesn't usually lead to infertility.

Chemotherapy

Chemotherapy drugs slow or stop cancer cells from growing, multiplying or spreading to other parts of your body. Many different types of chemotherapy and combinations of chemotherapy drugs are used to treat cancer.

Chemotherapy doesn't damage only cancer cells – it also damages healthy cells. This damage can cause side effects, but they usually go away when treatment is over. Some chemotherapy drugs can affect the way your sexual or reproductive organs work.

Chemotherapy and your sex life

Chemotherapy may or may not affect your sex life. Everybody reacts differently, even to the same drugs. Some side effects, such as fatigue and nausea, may affect your desire for sex. Hair loss, weight loss or gain, or having a port or catheter can make you feel less desirable.

During chemotherapy, some women get yeast infections, which can irritate the lining of the vagina and cause itchiness or burning during and after sex. Some chemotherapy drugs can cause hormonal changes that can make menstrual periods irregular or stop altogether. This can lead to side effects such as vaginal dryness, which can make intercourse uncomfortable.

For men, chemotherapy usually doesn't affect erections or ejaculation.

Men and women who've had genital herpes or genital warts may get them again during chemotherapy.

If chemotherapy damages your reproductive organs, you may not be able to get pregnant or father a child. These fertility problems can be temporary or permanent.

Hormonal therapy

Hormonal therapy drugs stop your body from making certain hormones or block the action of the hormones – this slows or stops the growth of cancer cells. The drugs can also lower the level of hormones in your body. If you have a cancer that needs hormones to grow (for example, some types of thyroid, prostate, uterus and breast cancers), your doctor may suggest hormonal therapy.

Hormonal therapy drugs may be used for only a short time or for as long as the treatment is working. Some side effects of hormonal therapy lessen as your body gets used to the change in hormone levels. Most side effects usually go away completely when you stop the hormonal therapy, but others can be permanent.

Hormonal therapy and your sex life

Hormonal therapy drugs may affect your sex life by causing side effects such as fatigue, low sex drive or nausea and vomiting. They may also cause weight gain, which can affect how you feel about your body and make you feel less desirable.

Most women can experience sexual pleasure and reach orgasm while being on hormonal therapy. Some women may have breast swelling, hot flashes or treatment-induced menopause (which may not be permanent). Other possible side effects include vaginal soreness, dryness or narrowing, which can affect sexual pleasure.

Men who have androgen deprivation therapy (ADT), a type of hormonal therapy that reduces testosterone levels, will find that they're less interested in sex. Other possible side effects are muscle loss, weight gain or growth of breast tissue, which can affect how desirable you feel. Sex is still possible during and after ADT, but it may be difficult to get and keep an erection or to reach orgasm. You may need to use sexual aids or consider sexual activities that do not involve an erection.

Some hormonal therapies can cause fertility problems, at least for a period of time. Not all hormonal drug treatments lead to permanent infertility – it depends on the drugs you're taking, your age and your general health.

Do you need more information on treatment?

If you need more information about your treatment, or if the type of treatment you're having isn't listed in this chapter, we can help.

- Call our Cancer Information Service at 1-888-939-3333. It's free and confidential.
- Look for more in-depth information on cancer.ca.

Dealing with symptoms and side effects



“ You have to live your way back into a comfortable place for yourself. ~ Jess*

For men and women

It's almost impossible to predict how cancer and its treatment will affect you sexually – it depends on the type of cancer, the treatments you have and how your body reacts. How you feel about yourself as a sexual person can also be a factor.

It's important to note that many side effects that change how your body works sexually go away soon after treatment. You may only need to change the way you're doing things for a short while. If cancer and its treatment cause longer-lasting or permanent changes, you can explore, adapt and discover new ways to give and receive sexual pleasure.

“ It's a traumatic experience, physically, emotionally, mentally, spiritually, from each partner's side. You need to be gentle and patient with each other – and open to new and different ways to love each other. ~ Dana*

Fertility problems

Sometimes treating cancer can lead to infertility. Infertility is the inability of a man to father a child or a woman to get pregnant.

Talk to your doctor before treatment starts

You may not be thinking about fertility when you plan your treatment. But if there is any chance that you may want a child, even many years from now, it's important to talk to your doctor *before* treatment starts. Many people regret not asking about their options before treatment.

The treatment options may include:

- using surgical methods that don't affect fertility
- protecting organs with shields during radiation therapy
- moving ovaries (temporarily) away from the area being treated with radiation

Infertility can happen:

If the reproductive system is damaged. The risk of damage depends on the type of cancer and treatment you have. For example, if a woman's uterus is removed, there is nowhere for a baby to develop. If a man's prostate is removed, he doesn't produce any semen. Or if he can no longer get and keep an erection because of nerve damage, this can affect his ability to father a child.

When the testicles stop producing sperm (or produce less of it) or produce damaged sperm. For example, chemotherapy or hormonal therapy may mean your body produces less sperm, while radiation therapy to the pelvic area may mean your body makes unhealthy sperm that can't fertilize a woman's egg.

When the ovaries release fewer eggs or stop releasing eggs. For example, radiation therapy can damage the ovaries and lead to early menopause. Chemotherapy and hormonal therapy can affect menstrual periods and cause the ovaries to stop releasing eggs.

Infertility can be temporary or permanent, depending on:

- your age
- your fertility before cancer treatment
- the area being treated
- the type and dose of treatment
- the length of time since treatment

Feelings about infertility

It can be devastating to learn that the cancer treatment you need may cause infertility. It's natural to feel a great sense of loss. For some people, this feeling comes later on, when they are thinking of having children. If these feelings become hard for you to cope with, ask your doctor about talking to a counsellor.

> TIPS

- Explore options that allow you and your partner to delay decisions about having children. These include sperm banking or freezing of sperm and freezing of eggs or fertilized embryos (where a woman's eggs are removed, fertilized with her partner's sperm, frozen and stored).
- Ask about success rates, costs, and risks and benefits of different reproductive techniques.
- Think about other options for becoming parents such as adoption or surrogacy (where another woman carries and gives birth to the child for the genetic parents).

Hot flashes

“ *The sweat, the heat. The middle of the night, I have to sit up because it almost makes it hard for me to catch my breath. Sometimes it almost brings you to tears – you are so fed up with it.* ~ Paul

You may be surprised that this comment is from a man. Both men and women taking hormonal treatments for cancer may experience hot flashes and sweating caused by changes in hormone levels. These side effects usually calm down as your body gets used to the treatment or when therapy is over.

Hormonal therapy isn't the only treatment that causes hot flashes. Women who have their ovaries removed or whose ovaries are affected by chemotherapy or radiation can get hot flashes too.

If certain foods or drinks are making hot flashes happen more often, a dietitian may help you figure that out. Talk to your doctor about medications to help you if your symptoms are severe.

> TIPS

- Wear light clothing in layers that can be removed.
- Carry a face cloth in your bag when you go out. If you have a hot flash, run cold water on the cloth and use it to cool yourself down.
- Relieve hot flashes by splashing cool water on your wrists or rolling a cold bottle or can of pop or juice between your wrists.
- Exercise regularly and learn relaxation techniques.
- Try to identify what triggers hot flashes, such as alcohol, hot drinks or anxiety. Then avoid them as much as you can.

Incontinence

“ At the end of the day, you are usually tired physically and that also affects the muscular fatigue and makes the incontinence worse. So night time is probably not the best time for sex. ~ Dan

Cancer and its treatments can sometimes lead to a temporary or permanent loss of control over your bladder and bowel (incontinence). There are a number of reasons why this might happen including infection, a blockage, inflammation, nerve or muscle damage and side effects of medications.

Being incontinent can make you feel awkward or embarrassed. But it's important to know that incontinence doesn't affect your physical ability to have sex.

> TIPS

- Plan sexual activities at a time of day when you're least tired. This is when your muscles are more likely to be at their best.
- Empty your bladder and bowel before sex.
- Try having sex in the shower or bath.
- Wear a condom when you're having sex.
- Avoid alcohol and caffeinated beverages that can over-stimulate the bladder.

- Avoid spicy foods, carbonated drinks, citrus and fruit juices that can irritate the bladder.
- Retrain your bladder by emptying it often or on a schedule. Gradually increase the time between urinations.
- Practise Kegel exercises.

Kegel exercises

Kegel exercises can make your pelvic muscles stronger and make your bladder work normally again. They can be done sitting, lying or standing.

- Tighten or squeeze the muscles around the anus as if trying to prevent gas from passing. This locates the correct muscles. (Try not to contract abdominal, back or thigh muscles or hold your breath.)
- Hold the squeeze for a count of 3, then release slowly for a count of 3.
- Repeat 10 times for one set. Try to do 5 sets a day – for a total of 50 Kegel exercises.

You can do these exercises any time – while watching TV, sitting in your car at a red light or waiting to pay in a store. No one can tell!

If these tips aren't enough, ask your doctor if anything else can be done. Medications or other treatment options, including surgery, could work for you.

Living with a stoma

Having an opening in your body to remove stool or urine, or to allow you to talk and breathe, can affect your confidence, your self-image and sometimes your ability to communicate. It can make you anxious and distract you during sex. Try not to place too much importance on a stoma when it is such a small part of you. A fulfilling sex life is still possible – it just might take some planning.

It takes time and patience to learn to care for a stoma after your surgery. You can get help from healthcare professionals called *enterostomal therapists*. They teach ostomy care after surgery and offer support and advice once you're home.

> **TIPS** if you have a colostomy or urostomy

- Make sure that your bag (which collects the stool or urine) fits well. Before sex, change your pouch and check the seal to prevent leaks.
- Try having sex in the shower or bath.
- Get an attractive, non-medical looking cover for your bag. Or use a fabric sash or cummerbund.
- Wear a special smaller-sized pouch, or use a cap or plug if you have a colostomy.
- Wear whatever makes you feel good. Some people prefer to wear a T-shirt during sex to cover their pouch.
- Tape the pouch to your body to stop it from flapping during sex.
- Try sexual positions that keep your partner's weight off your stoma, such as lying side by side. If you prefer being on the bottom during sex, place a small pillow above your pouch and let your partner lie on the pillow instead of on the pouch.
- Wear cologne or after-shave to help with odours and avoid garlic or spicy foods.

> **TIPS** if you've had a laryngectomy

- Discuss what you both like sexually before starting. You can develop ways of signalling messages to each other during sex.
- Say what you need to say by guiding your partners' hands or using body language.
- Wear a stoma cover or scarf during sex if you think it looks more appealing than a bare stoma. Some men wear an ascot, while women wear a necklace.
- Avoid garlic or spicy foods to help with odours.
- Let partners know that they may feel your breath in spots that seem strange at first.

Loss of a body part

“ *I didn't want to be missing a body part. I was terrified of having a side with no breast. That was the part that gave me the most anxiety.* ~ Jess*

Losing any body part to cancer can be physically and emotionally devastating. It can affect your body image – the way you picture yourself. It can cause feelings of grief, loss, anger, embarrassment and inferiority. The reactions of other people can make these feelings seem worse.

All of this can affect your sexual desire and your confidence in yourself as an attractive, sexual person. Try to get your feelings out in the open and talk about them – with your healthcare team or a therapist, your partner, a family member or a trusted friend. It's natural to try to hide a change to your body or to avoid looking at it. But this can make you feel more and more anxious about the issue or being found out. Explore what you fear most and how you might deal with that. Over time, you can feel confident again.

In some cases, reconstructive surgery to rebuild or partially rebuild a body part may help you feel better about yourself.

If you're the partner of someone who has lost a body part to cancer, you may also find that talking helps. It's quite normal for you to feel uncomfortable with the changes to your partner's body – and quite normal to then feel guilty about this. For many, it takes time to come to terms with the changes. But if you work it out together, you can regain intimacy.

“ *Not everyone wants attention brought to their scars or cancer-induced imperfections, especially during intimate moments. However, for me, a partner who sees beauty and strength in the scars on my body helps me see my beauty and strength.* ~ Dana*

> TIPS

- Focus on the things you think are most attractive about yourself.
- Try having sex partially clothed instead of naked, if it makes you feel more comfortable.
- Turn the lights down low or keep them off when you're having sex if it helps you feel better.
- Try different positions during sex to discover what's most comfortable for you. Use pillows to help with positioning and support.
- Experiment to discover what works best for you. If you wear a prosthesis, such as an artificial arm or leg, keeping it on might help with positioning and movement during sex. Or you may find the straps used to hold the prosthesis in place are uncomfortable and get in the way.

Loss of sex drive

“ I was very afraid of living together like a brother and sister. It feels like you're going to move into this platonic sort of relationship where there's none of that wonderful thing that you had as husband and wife. ~ Louis* and Zara*

Losing interest in sex doesn't happen to everyone during treatment, but it's a common experience. And it can be very upsetting for you and your partner. There are many reasons why sexual desire might drop, such as:

- fatigue
- pain
- anxiety, fear, frustration or stress
- depression
- physical changes or changes in appearance
- changes in hormone levels caused by cancer or its treatment

If your sex drive is affected, try to remember that sexual interest often returns when treatment is over and you're feeling better.

If depression might be affecting your sex drive, ask your doctor about treatment options. As well, you can always ask to see a sexual counsellor or healthcare professional who specializes in sexual problems.

> TIPS

- Speak openly and honestly with your partner about the changes you're going through. Explain how and why you feel this way.
- If loss of sex drive is caused by fatigue, try having sex in less energetic positions – make sure your partner's weight is supported well to reduce the strain on you. If a position makes you tired, try a different one.
- Ask your partner to take on a more active role.
- Try having sex at your least tired time of day.
- Have a nap before sex.
- Change the venue. If your home is where you and your partner are coping with side effects and your partner is helping you with personal care, plan a night away somewhere. Try using different rooms in the house. Or change the bedroom around.
- Try using sex videos or sex toys to spark your interest. If you don't have a local store or are embarrassed about going in, there are online suppliers that can send products in plain packaging to your home.
- Consider touching, hugging, holding and kissing your partner even when you don't have the desire or strength for more. If you wait to feel desire before you touch one another intimately, you may miss out on chances for sexual closeness and pleasure.

“ I was relieved that he still wanted to cuddle, kiss and tell me he loves me. I thought if the libido was gone, that all that good stuff would be gone. But it wasn't, so that was great. ~ Ali* and Terry*

Another idea is to keep a desire diary. Each day for a week, notice when you have a sexual thought or feeling and write it down. Note the time of day, the setting or what made you feel more sexual. Check your notes for patterns and share them with your partner. Once you see a pattern, you can put yourself in situations that lead to a sexual mood – such as reading a novel with steamy sex scenes or fantasizing about a sexual encounter.

“ *The interest in sex is still there, but it can be buried under layers of worry, hormones and feelings. It’s good to explore different ways of getting it back, like watching sexy movies or fantasizing.* ~ Jess*

Pain and discomfort

If you feel pain anywhere in your body, it can easily turn you off having sex. Or pain may make it hard for you to have sex in the positions you used in the past. You may be afraid that sex will hurt. This can reduce your desire for sex, prevent natural lubrication and distract you from reaching orgasm. And if you can’t relax, it can lead to more pain and tension.

Talk to your healthcare team if you have pain during sex or pain that stops you from having it. They can try to find the cause and suggest solutions.

> TIPS

- Take pain-relieving medication before sex.
- Have sex at the time of day when you feel the least pain.
- Try relaxation techniques like warm baths, massage or gentle touching to decrease pain levels, to relax or for foreplay.
- Use a generous amount of water-based lubricating gel around and in the vagina before intercourse.

- Focus on feelings of excitement and pleasure to stop you focusing on the pain.
- Let your partner know what causes you pain. Explore different positions or ways of having sex that may be more comfortable. Try a side-by-side position to reduce body weight on a sore area, scar or stoma. Use pillows and cushions for comfort and support.
- Avoid deep pelvic thrusts as this may cause pain.
- Try to be close to orgasm before penetration.

Alternatives to penetration

If you’re experiencing pain during penetration you might try:

- cuddling and touching
- massage
- manually stimulating each other
- oral sex
- showering or bathing together
- watching erotic videos
- sex toys that can be used externally
- self-stimulation or masturbation

For women

Difficulty reaching orgasm

If you were able to reach orgasm before cancer treatment, you may be able to again. But cancer and its treatment can make it harder to get there. And fears about feeling pain and worries about reaching orgasm can get in the way.

Your physical ability to reach orgasm isn't usually affected unless cancer treatment has damaged your spinal cord, causing your genital area to become numb. Cancer surgery may remove sensitive parts of your body such as the clitoris, lower vagina or vulva. You also need time to get used to new feelings or sensations during sex. A sexual counsellor can help.

> TIPS

- Give yourself time, and practise to figure out what works for you. Be patient with yourself.
- Set the mood with soft lighting, candles and music.
- Place your partner's hands and fingers on areas that arouse and excite you – or do it yourself. Try a hand-held vibrator for extra stimulation.
- Use plenty of water-based lubricant.
- Have a sexual fantasy during lovemaking. This can distract you from negative thoughts and fears.
- Try different leg positions. Some women achieve orgasm more easily when their legs are open and thigh muscles are tense while others prefer to press their thighs together.
- Try tightening and relaxing your vaginal muscles in a rhythmic pattern during penetration or while your clitoris is being stroked.
- Look for books or videos that provide ideas about how to reach orgasm.

Early menopause

“ I was only in my thirties, and I went into menopause overnight. The hot flashes, vaginal dryness and the emotions. I was crying at car commercials. ~ Dana*

Menopause is the time in a woman's life – usually between the ages of 45 and 55 – when the ovaries stop producing estrogen and menstrual periods stop. If your ovaries are removed because of cancer or are affected by chemotherapy or radiation to the pelvis, loss of estrogen can cause early menopause.

Early menopause can cause more severe symptoms than natural menopause. Your interest in sex may decrease, and you may experience hot flashes, sweating, vaginal atrophy (when the vagina becomes tight and dry), irritability or changes in sleep patterns. If your menopausal symptoms are severe, consider talking to your doctor about the risks and benefits of using hormone replacement therapy (HRT) or other medications to help control them.

> TIPS

- If vaginal dryness is a problem, use lots of water-based lubricants during sex.
- Exercise regularly and explore relaxation techniques.
- Wear light clothing in layers that can be removed and put back on if hot flashes are an issue.
- If you're struggling with your emotions, talk to your doctor about seeing a counsellor.

Vaginal dryness

“ Chemo put me into menopause, which is fine. I like not having periods ... but the vaginal dryness was terrible and intercourse was so painful. ~ Marie* ”

Chemotherapy, hormonal therapy and radiation therapy to the pelvic area can reduce the amount of moisture that your vagina produces when you're sexually excited. Menopause caused by treatment can also lead to vaginal dryness. And when the vagina is dry, sexual intercourse can be painful.

After assessing the cause, the type of cancer you've had and how severe your vaginal dryness is, your doctor may suggest creams or medications (such as hormone cream or hormone replacement therapy) to help.

> TIPS

- Use a water-based lubricant to make penetration during sex more comfortable. Re-apply as many times as you need to during sex. Lubricants can also help if you're using a dilator after radiation therapy.
- Choose lubricants that don't contain perfume, colouring, spermicides or chemicals. These can irritate the tissue of the vagina. Ask your pharmacist to help you pick ones that are safe to use. Try different kinds to find out which works best for you. Petroleum jelly or other oil-based lubricants can cause infections, so it's best not to use them.
- Ask about over-the-counter moisturizers that bind to the vaginal wall and reduce dryness for a few days at a time. They can help with day-to-day discomfort (for example, burning and stinging when walking, exercising or getting up from sitting). Using them regularly can also make sexual touching and penetration more comfortable. Some women find that using a vaginal moisturizer means they don't need to use lubricants for sex.

Dana's story: Cancer treatment, sexuality and the journey back

Dana* was taking a break from a social work degree when she was diagnosed at age 31 with stage 3 ovarian cancer. Doctors took out her right ovary, but she also needed a second operation to remove her uterus, cervix, Fallopian tubes and other ovary.

The surgery caused many sexual side effects. "I remember the first time my partner and I tried to have sex," recalls Dana. She had pain and an unpleasant feeling inside and outside from the stitches. "It was hard to move around, to be sexual and 'into it'."

During surgery, the laser accidentally severed a nerve, so there was also a problem with her right leg. "In a sexual situation, I couldn't rely on using my leg to push up, move or thrust. It kept flopping all over the place." With a lot of pillows, Dana found she could keep her leg in place.

But there was something else to deal with – early menopause. Suddenly, she had hot flashes, mood swings and vaginal dryness. The dryness was a challenge for her as a lesbian. "Sex between women is often dependent on hands and fingers, both in foreplay and sexual acts. And with fingers, there are nails. And with vaginal dryness, things rip easily."

Lubricants helped, as did hormone replacement therapy (HRT), which Dana is on – for now. Aware of the risks of HRT, Dana regularly discusses the pros and cons with her doctor.

Dana's approach to sex has changed. "I'm not all about having an orgasm. I'm more about the journey." Over the years, she has had "patient partners who understood the fact that it takes longer for me to have an orgasm, because of nerve damage."

She also understands better what gives her pleasure and has learned the value of intimacy when one's body has gone through so much. "Having those moments with somebody you care about, and who cares about you, is important to recovery from cancer. It means so much when your partner doesn't care that you need help to be in certain positions or understands that your skin still hurts from your treatment and is happy just to hold you."

Vaginal narrowing

“ I didn't quite understand how things were sewn up inside ... so the vagina is actually shorter now. You find out the painful way when somebody runs into a dead end. ~ Dana*

Radiation therapy to the pelvic area or certain types of surgery can cause your vagina to become shorter and narrower. Radiation therapy and surgery can sometimes cause scarring, which can make the vagina narrower and less flexible.

It's important for you to stretch the walls of the vagina to keep it open. This can be done by having gentle sex regularly or by using a vaginal dilator (a plastic or rubber tube-like device that helps stretch out the vagina). Vaginal tissues may be sore and tender after treatment and for a few weeks or months after, so it's important to be gentle. You may need dilators of different sizes over time. You don't need a prescription to buy a dilator, but you will need help from someone on your healthcare team to know what size to buy and how often to use it. It can also be very helpful to self-stimulate or masturbate regularly, especially if you're not having sex with a partner. Sexual arousal from this increases circulation to the pelvis and the vagina. (This may be as important as dilation.)

If you're not interested in having sex, it's still important to use a dilator to keep your vagina healthy during healing. This also makes follow-up examinations of the vagina less painful.

For men

Changes in ejaculation

“ When I masturbated, the feeling would be the same because it's a muscle feeling, but there would be no ejaculate - or maybe a bit of dripping afterwards. ~ Paul

Cancer treatment may cause changes in the way you ejaculate. One of these changes is called dry orgasm. When you have an orgasm, there may be little or no semen released. But even with no semen, the feeling of pleasure caused by orgasm remains.

Surgeries that remove the prostate and the seminal vesicles, such as radical prostatectomy or radical cystectomy, always cause dry orgasms. A number of other surgeries can also cause this to happen.

Sometimes, surgery causes semen to go back inside your body instead of coming out. This is called *retrograde ejaculation*. It happens when the fluid carrying the sperm flows backwards into the bladder and mixes with urine instead of going out through the penis during ejaculation and orgasm. Retrograde ejaculation isn't harmful, but it does make you infertile. (If you want to have a child, doctors can extract your sperm as long as your body is still making it.)

Some men also leak urine during ejaculation. It may be only a few drops or a larger amount. For urine leaks, ask your doctor about using a constriction band, which is tightened at the base of the erect penis. This squeezes the urethra and keeps urine from leaking out.

These changes can be upsetting and embarrassing. It's important to give yourself and your partner time to get used to them, but you may also want to talk to your doctor about follow-up surgeries, medications or sex therapy that might help.

> TIPS

- Talk openly with your partner.
- Try longer foreplay to make sure you're as excited as possible when you ejaculate.
- Keep a towel nearby.

Erectile dysfunction (ED)

Many men find that surgery or radiation therapy to the pelvic area causes problems with erections – this is called *erectile dysfunction* (ED). Changes to hormone levels can also play a part in ED. But cancer treatment may not be the only cause. Emotions are powerful – worrying about being able to keep an erection may be part of the problem.

“*Expectation is a real factor. If you are told by every other patient and by doctors that you are going to be asexual, nothing affects sexual ability more than expectation.* ~ Mark*

ED may be temporary or permanent. Some men can get full erections again. The younger you are, the more likely you are to get your erections back after cancer treatment.

Ask about sparing nerves *before* surgery

Nerve-sparing surgery increases the chances of preserving erectile function. Depending on the type of cancer and the extent of surgery needed, you may be able to have it. Nerve-sparing surgery isn't possible for everyone, but it's an important issue to ask your doctor about *before* your operation.

If you're having erection problems, know that men can still have orgasms and be fertile with ED. Sex is possible with a half-erect penis. It works best with the partner on top guiding the penis inside. Experiment with other positions too.

“*Because my erections aren't as strong anymore, the best sensation for me is when I am behind my partner.* ~ Dan

If you continue to have problems with erections, you may want to talk to your doctor about other ways to help keep your penis erect, such as pills, injections, vacuum devices or surgery to put an implant into the penis. Your sex life will be different than it was before – and you may need help in adjusting. You may need to talk to a sexual counsellor who can help you and your partner communicate better and recommend sexual techniques to try.

> TIPS

- Keep trying. It can take a while to get used to new ways of doing things.

“*If a couple is going to try to pretend that nothing's changed, then they're going to be in worse shape. They have to accept that something has to be new. Sexual and intimacy adaptation is a first step.* ~ Mark*

- Be open with your partner about the changes and challenges you're facing. You can work together to find out what satisfies both of you.
- Go to a sex shop and try out the toys.

“*Talk to your partner and say, 'How about we make an outing of it? Let's go for lunch, and then we'll go to a sex shop and see what they have on the shelf.'* ~ Mark*

- Find ways to be sexually satisfied without penetration. What works for one man may not work for another. You can try:
 - > all-over touching
 - > oral sex
 - > masturbating or self-stimulating on your own or with a partner (be sure to use a lubricant when stimulating a limp penis)
 - > thrusting your penis between a partner's lubricated thighs
 - > using a dildo or vibrator to satisfy your partner

Mark's story: Prostate cancer and facing facts

Since his prostate cancer diagnosis 13 years ago, Mark* has had three types of treatment, each affecting his sexuality.

First came a radical prostatectomy to remove the prostate. Nerve-sparing techniques could not be used because the tumour was too large.

The surgery had a major sexual impact. "I was impotent," says Mark. "I also had minor incontinence, though I eventually got control over that."

Despite surgery, Mark's prostate-specific antigen (PSA) level, a marker for prostate cancer, continued to rise. Doctors recommended radiation treatment to the area where the prostate used to be.

In addition to being impotent, Mark was told that he was sterile from radiation to the testicles, which produce sperm. And still his PSA level was climbing.

Mark then turned to androgen deprivation therapy (ADT), a type of hormone therapy that lowers levels of androgens (hormones such as testosterone) that stimulate growth of prostate cancer cells.

Being "chemically castrated" lowered his sex drive. He felt emasculated. Mark admits that his way of dealing with this was unusual – he began reading about eunuchs.

"I knew they'd been castrated, but I found out to my surprise that they weren't asexual, at least not always, nor disempowered. Some women pursued eunuchs as sex partners in the Roman Empire. Casanova talked about having sex with eunuchs. They were the people who ran the major governments of Asia for 3000 years. So I realized, mentally, that I didn't have to be asexual or disempowered ... and I'm not."

Exercise helped him deal with other ADT side effects, including weight gain, loss of muscle mass, fatigue and occasionally depression.

Mark also came to terms with another side effect – enlargement of the breasts. Taking his shirt off to exercise isn't a big deal now. "If you're not going to exercise because you're ashamed of your body, then you're not helping at all. It's important to recognize the reality of what's happened and accept it."

And, of course, "having a fabulous partner helps."

"Androgen deprivation has major effects, but one can live with them," says Mark. "And, as history has shown, given the right motivation there are ways to maintain sexual intimacy and even be orgasmic despite impotence and little or no testosterone."

Emotions, confidence and self-esteem



“ *It was such an emotional experience for me. It was up and down ... I didn't get the emotional support that I needed. I think I went through a lot of trouble that I didn't have to. ~ Jess**

Cancer can affect your emotions, confidence and self-esteem. It can cause fear, anxiety and depression that go beyond the physical side effects of cancer and its treatment. These feelings can be as serious as the physical effects of cancer. And partners can have them too. These emotional “ups and downs” can affect your desire for sex. And if you already feel bad and a sexual experience doesn't go how you hoped it would, you may feel worse.

Don't ignore the emotional changes cancer can cause. Tell your partner how you're feeling. Support groups or talking to someone else with cancer or other caregivers can also help. If your emotions become too much for you to cope with, talk to your doctor. There are many treatments, including medication and counselling, that may help you.

“ *I realized that you can't be constantly thinking, 'I'm going to die.' Because you are no longer living if you think you are going to die all the time. So ... I chose to live, even though my life is very different now. ~ Mark**

Body image

“ For me, body image was the largest issue ... I was trying to get to a place where I could feel like I could wear normal clothing ... I wanted to feel like my shape wasn't deformed. ~ Jess*

When cancer and treatment change the way you look, your self-esteem, sex drive and sex life can really suffer. You may find you focus a lot on the physical changes caused by cancer. For example, you may need to get used to hair loss, changes to skin and nails, weight loss or gain, scars or loss of a body part. Even if you look much the same on the outside during or after your cancer experience, you may feel less attractive or desirable. All of these things can affect your sex life, and everyone reacts in their own way.

“ The ADT (androgen deprivation therapy) caused my body hair to disappear. I gained about 15 pounds, and I have some breast development and genital shrinking. My body changed, and it doesn't look like your typical male body quite as much. ~ Mark*

Jess*, who had a mastectomy for breast cancer, remembers feeling self-conscious and embarrassed about the shape of her body. She was surprised to find that, when she dressed up and went dancing with friends, men still looked her way. “I felt like my whole body was deformed, but people didn't seem to notice. I thought, ‘Most of this is in my head.’”

Changes to your body may be temporary or permanent, but there are ways to improve your body image and your self-esteem when you have cancer.

> TIPS

- Talk to your partner or someone else you trust about your fears and feelings.
- Focus on what makes you feel good about yourself. This can reduce anxiety and build confidence.
- Try masturbating or self-stimulating. It may make you feel better about your body and prove to yourself that you can feel sexual pleasure.
- Wear lingerie, pajamas or a top so you are partly dressed during sex. You may feel more comfortable at first if you cover the change to your body.
- Dim or turn off the lights during a sexual encounter if this helps you feel more relaxed.
- Try different positions that help you relax, such as facing away from your partner during sex.
- Consider wearing a prosthesis – for example, an artificial limb may help with positioning and ease of movement during sex.
- Take care of yourself and indulge in little splurges if you can. A hair cut, new item of clothing, massage or pedicure can help you feel better about yourself.

If these tips aren't enough, ask your doctor if anything else can be done. In some cases, plastic surgery can make your body look more like it used to or counselling may help you get used to changes.

The mirror exercise

This exercise can help you get used to a change in your appearance and remind you of your positive qualities. It can help you feel more relaxed when being sexual with a partner.

Find a quiet time to do this exercise on your own. Look at your entire body in a mirror and then focus on the part that has been changed by cancer. It may be hard at first, but relax and take your time. Now, find at least three good things about your body or appearance. Repeat the exercise as many times as you need to until you feel comfortable looking at yourself in the mirror.

After cancer, some people decide to embrace the changes to their body, and even draw attention to them. Marie*, a breast cancer survivor, took a creative approach to reconstructive surgery. “I had reconstruction,” she says, “but I didn’t have the nipple put on. Instead, I got a daffodil tattoo in its place. Of course, it’s pretty limited who can see it!”

Some people say the relief of having the cancer removed makes up for the changes to their body.

“*It took me a while to get used to the scar. But because there was so much physical relief after the tumour was out, it actually made me more comfortable with myself.* ~ Dana*

Jess’s story: Learning to feel good again

For Jess*, diagnosed with breast cancer in her twenties, the emotional ride was the hardest part.

“I felt completely knocked off course,” says Jess, who was just returning to work after maternity leave.

When she thought about having a mastectomy, “I was terrified of waking up without a breast.” So Jess asked to have breast reconstruction at the same time. Unfortunately, after the surgery, her body didn’t react well to the implant, and it had to be removed. Jess was told she couldn’t have reconstruction again for a year.

The following months were hard. Jess didn’t like the way her clothes fit when she wore a prosthesis. “I enjoy fashion and have worked as a model, so I’m aware of clothes and body shape.” She was annoyed by fashion ads and the sight of girls at the beach. More than anything, she was angry at herself.

“When you have a strong body growing up, and you are athletic and feel in control, this feels like a betrayal.”

Jess didn’t recognize the signs of depression – but her family did. Her doctor prescribed medicine for anxiety and depression.

Her husband was patient and understanding. He looked for clues to know when she wanted to be intimate. They had late-night talks about how she was feeling and, sexually, what felt right. Taking holidays helped “because it was outside our regular emotion of being home.” So did new lingerie and wearing a top in bed – although, after a while, Jess didn’t need it.

Then came a “milestone moment” when Jess agreed to model for a breast health fundraising calendar. “I still didn’t have a breast, and I felt proud that I could get together with a group of women to support each other and display what had happened and not feel unattractive.”

Reconstructive surgery, when it happened, took place at the same time as a career change. “I started to feel a lot better about myself. I was back into work, buying nice clothes, feeling pretty, and I felt I was contributing to society.”

Swimming was part of her routine. In fact, it was at the pool that Jess realized she wasn’t angry at her body anymore.

“Usually, when I was changing, I went into a corner in the change room and covered myself with a shirt so nobody would be shocked. But after a while, I noticed I wasn’t doing that anymore. And nobody was looking. All of a sudden, I felt like anybody else in the change room.”

Fear and anxiety

A cancer diagnosis can make both you and your partner fearful and anxious, which can affect your sex life and your sexuality in many ways.

Worries about cancer may make you less interested in sex, and you may find yourself avoiding it. You may worry about your sexual abilities and ask yourself questions – “Will I be able to get an erection?”, “Will sex be painful?” or “Will I still be able to reach orgasm?” Again, these doubts and fears may lower your sex drive and make you avoid sex. These feelings can make you withdraw, which leaves your partner feeling alone. One woman describes her husband’s reaction to having cancer this way:

“*He just kind of cut himself off altogether. He didn’t talk to me at all. He would answer me if I spoke to him but he didn’t initiate any conversation at all.* ~ Sophie* and Leo*

Partners can struggle with fears and anxieties that affect their own sexual behaviour. For example, they may worry about starting a sexual activity for fear of hurting the person who has cancer.

These feelings are normal – and you can both work through them. If you or your partner need help coping with sexual fears or anxiety, talk to someone on your healthcare team about counselling.

> TIPS

- Take some time on your own. Try touching different parts of your body to see if you feel pleasure. If your body responds, this may calm your fears about being sexual with your partner.
- Talk to your partner about your anxiety and fears. Nobody goes through a cancer experience without some of these thoughts. By sharing them with your partner, you show you trust them to help you through this tough time. Being close like this can support and reassure both of you.
- Schedule some relaxing time together. Start with a touching session that avoids sensitive or erogenous zones. Go slowly.

Some say that the strong emotions that come with cancer and its treatment can actually add to a relationship.

“*He’s full of romance. He loves to be mushy ... He’s a lot more romantic than he used to be.* ~ Monique* and John*

Sadness and depression

“*Some days I had good days and some days I didn’t. He never knew what to expect from me ... I think that must have been hard on him, trying to read the signs.* ~ Jess*

After a cancer diagnosis, it’s normal to feel sad and unhappy over the loss of good health and your normal day-to-day life – including your sex life. Partners can feel sad and unhappy too.

> TIPS

- Talk to your partner, a close friend or family member, or a spiritual care worker about your feelings.
- Eat well and be physically active. Talk to your doctor about what type of exercise is right for you. You may want to try meditation or yoga.
- Talk to someone with a similar cancer experience.

Finding support

Support groups can be very helpful when you're going through the emotional ups and downs of cancer. They are safe places to talk about feelings and how you're doing. These groups often meet in person in your community, at a cancer centre or hospital, or they can be online or on the phone. Cancer support groups allow you to reach out to others who've been through a similar experience. Just being part of a community like this can help you feel better.

"I never thought I would join a group! But in a group, you don't feel that you are all alone. You don't have to speak if you don't feel like speaking. You can listen and learn and see that you are not by yourself." ~ Paul

If a group isn't for you, you could try one-to-one support by telephone or in person.

Our Cancer Information Service can help you find what's available in your community.

- Call us toll-free Monday to Friday at 1-888-939-3333 (TTY 1-866-786-3934).
- Email info@cis.cancer.ca.
- Visit cancer.ca.

Want to connect with someone online?

If you'd like to connect with someone online, join our online community, CancerConnection.ca. There are discussions and groups that may interest you, and you'll find caring, supportive people there.

Signs of depression

When a sad, despairing mood won't go away or gets worse over time, you may have clinical depression. Depression can and should be treated. It's an illness like any other – it's not a sign that you failed or can't cope. It's easy to miss the signs of depression – but recognizing it is the first step to feeling better. Treating depression can improve your sleep, appetite, energy and self-esteem and help you feel pleasure.

“ *The isolation and loneliness just fell down upon me so fast and hard that it was obvious to others that something was really wrong.* ~ Jess*

If your desire for sex is affected because you're depressed, talking openly about how you feel can help you and your partner feel more secure in your relationship. This can be such a confusing time for both of you – admitting how confused and uncertain you feel can help bring you together emotionally.

What to watch for – Possible signs of depression

- not sleeping or sleeping too much
- overeating or having no interest in eating
- crying a lot
- loss of interest in sex
- feeling hopeless
- thoughts of harming yourself

"Don't do what I did – don't wait too long to go to the doctor. When you see the signs of depression, go ... It helps to talk about your issues, and a good psychiatrist guides you and helps you understand the situation." ~ Paul

Talk to your doctor or a member of your healthcare team if you have any of these signs of depression. You may need to be referred to a psychiatrist or mental health professional. It's important to note that partners can be depressed too and may need treatment.

Treatment may include medication (antidepressants), counselling or both. If you need medication to treat depression, talk to your doctor about possible side effects. Some antidepressants can decrease sex drive and make it hard for you to reach orgasm. If you have these sexual side effects, you may be able to try different dosages or different types of antidepressants.

Moving forward



“ Sometimes, it feels like it’s impossible for things to feel okay again. But there is a place that you can get to, and you can’t really get there without a lot of patience. It’s not instantaneous. ~ Jess*

At times, you may feel like sex will never be the way it was. For some people, sex will definitely be different. You may have to think of sexuality in a new way. You may need to experiment and explore new ways of doing things – and you’ll need to talk about what works and what doesn’t.

But it’s possible to have satisfying sexual relationships – to feel pleasure, intimacy and a physical connection. It just may take time to get there, along with patience, determination and hope.

“ We’ve sort of reached out and grabbed each other’s hand and jumped, and we’re hoping one of two things will happen – that there’s a soft landing or somebody teaches us how to fly. ~ Ian*

“ You may experience a redefinition of sexuality and yourself and, through the cancer experience, you may come to realize a richer experience of sexuality than you ever thought possible. ~ Dana*

“ I think we’ve come to terms with what’s more important in our lives. Whether sexuality takes a front row seat or maybe it’s just two rows back – we’re okay with that. It doesn’t change the way we feel for each other. ~ Dan



Canadian Cancer Society

The Canadian Cancer Society fights cancer by doing everything we can to prevent cancer, save lives and support people living with cancer.

Getting the information you need

Our trained information specialists take the time you need to answer your questions over the telephone and by email. If you need information in a language other than English, interpreters are available. We have the information you need about:

- cancer treatments and sexual issues
- managing side effects
- living with a stoma
- finding a counsellor

Through our Community Services Locator, we can help you find services and programs in your community that are offered by the Canadian Cancer Society and other organizations.

Here are some other booklets we recommend. You can find them and others in print and online.

Living with Cancer: A guide for people with cancer and their caregivers

Chemotherapy and Other Drug Therapies: A guide for people with cancer

Radiation Therapy: A guide for people with cancer

Pain Relief: A guide for people with cancer

Complementary Therapies: A guide for people with cancer

Life after Cancer Treatment

Advanced Cancer

Note: These titles may change when new versions are published.

Talking to someone who's been there

If you would like to talk to someone who's had a similar cancer experience, we can help. Let us connect you with a volunteer who can listen, provide hope, offer encouragement and share ideas for coping – all from the unique perspective of someone who's “been there.”

If you'd like to connect with someone online, join our online community, CancerConnection.ca. There are discussions and groups that may interest you, and you'll find caring, supportive people there.

To contact the Canadian Cancer Society:

- Call us toll-free Monday to Friday at **1-888-939-3333** (TTY 1-866-786-3934). If you need help in another language, interpreters are available.
- Email info@cis.cancer.ca.
- Visit cancer.ca.
- Contact your local Canadian Cancer Society office.

Our services are free and confidential



Suggested websites and books

The Canadian Association for Enterostomal Therapy

www.caet.ca

The Canadian Continence Foundation

www.continence-fdn.ca

United Ostomy Association of Canada

www.ostomycanada.ca

National Cancer Institute

www.cancer.gov

Search for > Sexuality

Search for > Life after treatment

American Cancer Society

www.cancer.org

Search for > Cancer, sex and sexuality

Katz A. *Man Cancer Sex*. 2009. Pittsburgh: Hygeia Media.

Katz A. *Sex When You're Sick: Reclaiming sexual health after illness or injury*. 2009. Westport, CT: Praeger Publishers.

Katz A. *Woman Cancer Sex*. 2009. Pittsburgh: Hygeia Media.

Kaufman M, Silverberg C, Odette F. *The Ultimate Guide to Sex and Disability: For all of us who live with disabilities, chronic pain and illness*. 2007. San Francisco: Cleis Press.

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Notes

Series of horizontal lines for taking notes.

Notes

We'd like to hear from you

Email us at publicationsfeedback@cancer.ca if you have comments or suggestions to help us make this booklet more useful for you and other readers.

What we do

The Canadian Cancer Society fights cancer by:

- doing everything we can to prevent cancer
- funding research to outsmart cancer
- empowering, informing and supporting Canadians living with cancer
- advocating for public policies to improve the health of Canadians
- rallying Canadians to get involved in the fight against cancer

Contact us for up-to-date information about cancer and our services or to make a donation.



Canadian Cancer Society
Société canadienne du cancer

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It is not intended to replace the advice of a qualified healthcare provider.

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