

Sexuality, Intimacy and Cancer

A guide for people with cancer and their partners



For information & support, call **13 11 20**

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Sexuality, Intimacy and Cancer is reviewed approximately every three years.

Check the publication date above to ensure this copy is up to date.

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Note to reader

Always consult your doctor about matters that affect your health. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for medical, legal or financial advice. You should obtain independent advice relevant to your specific situation from appropriate professionals, and you may wish to discuss issues raised in this book with them. All care is taken to ensure that the information in this booklet is accurate at the time of publication. Please note that information on cancer, including the diagnosis, treatment and prevention of cancer, is constantly being updated and revised by medical professionals and the research community. Cancer Council Australia and its members exclude all liability for any injury, loss or damage incurred by use of or reliance on the information provided in this booklet.

Cancer Council

Cancer Council is Australia's peak non-government cancer control organisation. Through the eight state and territory Cancer Councils, we provide a broad range of programs and services to help improve the quality of life of people living with cancer, their families and friends. Cancer Councils also invest heavily in research and prevention. To make a donation and help us beat cancer, visit cancer.org.au or call your local Cancer Council.



Cancer Council acknowledges Traditional Custodians of Country throughout Australia and recognises the continuing connection to lands, waters and communities. We pay our respects to Aboriginal and Torres Strait Islander cultures and to Elders past, present and emerging.



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About this booklet

This booklet has been prepared to help you understand the ways cancer and its treatment may affect your sex life and relationships. It does not need to be read from cover to cover – just read what is useful to you.

Sex and intimacy are an important part of our wellbeing. It's how we experience physical and emotional closeness, and develop intimate relationships. It's closely linked to how we relate to ourselves and others. We hope this booklet helps you find practical ways to adapt to any physical or emotional changes you experience, and discover ways to maintain intimacy.

The information in this booklet is for everyone, no matter what your sex, gender or sexual orientation, or whether you are in relationship or single. In this booklet, the term “partner” means the person/s you choose to share a close intimate relationship with.

When talking about the body, we use the terms “female” and “male”. Transgender, non-binary and intersex people may identify with a different sex or gender.

How this booklet was developed – This information was developed with help from a range of health professionals and people affected by cancer. It is based on research into sexuality after cancer treatment.¹⁻⁶



If you or your family have any questions or concerns, call **Cancer Council 13 11 20**. We can send you more information and connect you with support services in your area. You can also visit your local Cancer Council website (see back cover).

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More information



Alert



Tips



What are sexuality and intimacy?

The role that sexuality plays in your life is influenced by many things – including your role as a parent or partner, age, health, relationships, culture and beliefs, opportunities and interests, where you live, and how you feel about yourself (self-esteem).

Sexuality – This is about who you are, how you see yourself, how you express yourself sexually, and your sexual feelings for others. It can be expressed in lots of ways – such as the clothes you wear, the way you move, the way you have sex, and who you have sex with. Sexuality is about more than just your sexual orientation.

Sexual orientation – This refers to the attraction you feel towards another person. For example, you may identify as heterosexual (straight), homosexual (gay or lesbian) or bisexual (attracted to men and women).

Sex – This is more than just intercourse with penetration. Sex includes touching, kissing, masturbation and oral sex. It can be one way to experience intimacy, but intimacy isn't just about sex.

Intimacy – This is about feeling close to someone. This can be physically or emotionally. It can mean loving and being loved. It can be about showing mutual care and concern, or that you value someone and feel valued in return. Intimacy can be expressed in different ways. It may be through an emotional connection. You may share your thoughts and feelings with each other or share a special place or a meaningful experience. Even for those who don't have sex, intimate touch such as kissing, cuddling or holding hands is often still important.

Sexuality after a cancer diagnosis

Q: How does cancer affect sexuality?

A: Most people who have had cancer treatment say they experience changes in sexuality and intimacy.² For some it's temporary, while others need to adapt to long-term changes. Many people find this to be one of the hardest aspects of life after cancer.

Talking about how your sexuality has changed can be difficult. However, the challenges of a cancer diagnosis can also strengthen a relationship, improve how you communicate, and lead to new ways to express sexuality and intimacy.

The most obvious impacts cancer has on sexuality are physical. Treatment for some types of cancer can directly affect how you have sex, your enjoyment of sex or your desire to have sex (your libido).

A cancer diagnosis can also influence how you feel about your body (body image), your emotions and relationships. All of these can change how you feel about sex. The stress of a cancer diagnosis and treatment can affect these things too. Any stress you already had in your life or relationship may become more intense, so finding ways to manage this is important.

“Sex was the last thing on my mind when I found out I had cancer. I couldn't imagine ever having desire again. But after the treatment was over, it came back.” PAT

Q: Do people really think about sex when they have cancer?

A: For some, sex is the last thing on their mind after a cancer diagnosis and during treatment. For others, maintaining their sex life throughout this time is important. Having or returning to a fulfilling sexual and intimate life can allow people to reconnect to their body and partner again in a pleasurable way.

Q: Will my doctor talk to me about sex?

A: Sexuality is a normal and important part of health, but you can't assume your doctor will discuss it with you. Unfortunately that doesn't always happen. The topic may be overlooked for a variety of reasons:

- Your doctor may think that if you don't ask about sex, it's something that you don't want to talk about.
- There may not be the time or privacy needed for a lengthy or sensitive discussion.
- Your doctor may not feel comfortable talking about sex.
- You may not know that there are treatments available for many sexuality concerns, so you don't think to ask your treatment team.

Some cancer treatments directly affect sexuality, so knowing what to expect and how to have sex safely is important. During and after treatment you can ask questions, discuss any changes and share your concerns with your health care team (see opposite page). If they don't know how to help you, they can direct you to someone who does.

If you don't feel comfortable or safe talking with your health professional, speak to another person on the team or ask for a referral to someone else (e.g. you may prefer to see a female doctor).

Q: Who else can I talk to?

A: Talk to your general practitioner (GP), specialist or someone on your health care team who you feel comfortable with. They can refer you to a health professional who specialises in sexuality.

Health professionals who can help

| | |
|---|--|
| nurse | administers drugs and provides care, information, and support throughout treatment |
| cancer care coordinator | a specialist nurse who coordinates your care, liaises with other members of your health care team, and supports you and your family throughout treatment; care may also be coordinated by a clinical nurse consultant (CNC) or clinical nurse specialist (CNS) |
| continence physiotherapist | provides exercises to help strengthen pelvic floor muscles and improve bladder and bowel control |
| occupational therapist | assists in adapting your living and working environment to help you resume usual activities, including sex, after treatment |
| physiotherapist | helps with restoring movement and mobility after treatment, strengthening pelvic floor, and recommending aids and equipment |
| psychologist, counsellor, clinical psychologist* | help you manage your emotional response to diagnosis and treatment; provide support and advice about sexuality and intimacy |
| sexual health physician/doctor*, sex therapist | can help you, or you and your partner, with sexuality concerns before and after treatment |
| social worker | links you to support services and helps you with emotional, practical and/or financial issues |

** Specialist doctor*

Q: How soon can I have sex?

A: This depends on the treatment you've had and how fast you recover – both physically and emotionally. You can begin kissing or touching as soon as you want to. Ask your doctor when it will be safe for certain sexual activities, such as penetrative intercourse. This time is called a minimum waiting period. It is for medical reasons, and helps to prevent injury or infection after surgery.

It's normal to worry or be nervous about having sex again after cancer treatment. If you feel unwell you may not want to have sex, so don't feel pressured to do so before you're ready.

Q: Will I put my partner at risk?

A: Your partner cannot “catch” cancer from you. After some types of treatment, such as chemotherapy and radiation therapy, your doctor may advise you to protect your partner by using barrier contraception, such as condoms, or dental dams for oral sex, for a short time. Read more about *Safety concerns for partners* on page 65.

Q: Can sex make the cancer worse?

A: So long as you follow your doctor's time line of what's safe, sexual activity will not make the cancer worse or make it come back. In fact, the emotional benefits of physical affection or connection with a partner may help you to cope with treatment and recovery.

“My sexual partner has always wanted to have sex with me – this made me feel good about myself after my surgery.” DAPHNA



For tips from health professionals and personal insights about sexuality, listen to our “Sex and Cancer” podcast episode at cancercouncil.com.au/podcasts.

Q: Will I ever enjoy sex again?

A: Most people can have a fulfilling sex life after cancer, but you may need to learn different ways to give and receive sexual pleasure depending on what treatment you’ve had. Like any new skill, this can take time and practice. Some people say that because they try new things, their sex lives end up being better after cancer.

Q: How can we feel like sexual partners again?

A: During cancer treatment, relationships often change. Sometimes this happens gradually almost without noticing, and sometimes it is more sudden and obvious. Discussing the changes with your partner can feel awkward, but it’s an opportunity to develop ways to manage sexuality and intimacy. Spending time together as a couple can help build closeness. For ways to connect, see page 64.

Q: What if I don’t have a partner?

A: Sexuality is important whether you are single or in a relationship. Ask your treatment team about any concerns you have and when it’s safe to start sexual activity such as masturbation.

You may be worried about finding a new partner, and how you will tell them about the effects of the cancer. See page 32 for ways to talk to a potential partner. You can also ask for a referral to a sex therapist if you want to build up your sexual confidence.



The sexual response

Your interest in having sex is also called your sexual desire or libido. It is affected by your physical and emotional wellbeing, relationship satisfaction, body image, and levels of sex hormones, as well as the need to express love, give and receive pleasure, and create connection.

Sexuality starts in the brain. It is responsible for making you feel interested in sex through your memories, feelings and imagination. These thoughts are created by what you see, smell, touch, taste, hear and remember. The mind is also responsible for your body image – how you feel about your body and how you think it looks.

Stages of the sexual response cycle

Understanding what is happening to your body during sexual activity can be helpful. The sexual response cycle can be described in different ways. A common model includes several phases: desire, arousal (excitement), plateau, orgasm and resolution. These phases are the same for all sexes. The timing can be different for each person, and you may not go through all the stages. For example, you may experience pleasure without having an orgasm.

Erogenous zones

Areas of the body that can make you feel excited or aroused when they're touched or stimulated are known as erogenous zones. The main erogenous zones for most people are in the genital area: the clitoris, labia, vagina, penis, scrotum and anus. Other erogenous zones include the breasts, nipples, chest, mouth, ears, neck and inner thighs.

The role of hormones

Hormones are substances that affect how your body works. They act as messengers carrying information and instructions from one group of cells to another. Hormones control many of the body's functions, including how you grow, develop and reproduce. Everyone has hormones in their bodies in various levels: generally, men have more testosterone and women have more oestrogen and progesterone. This may vary for transgender or intersex people.

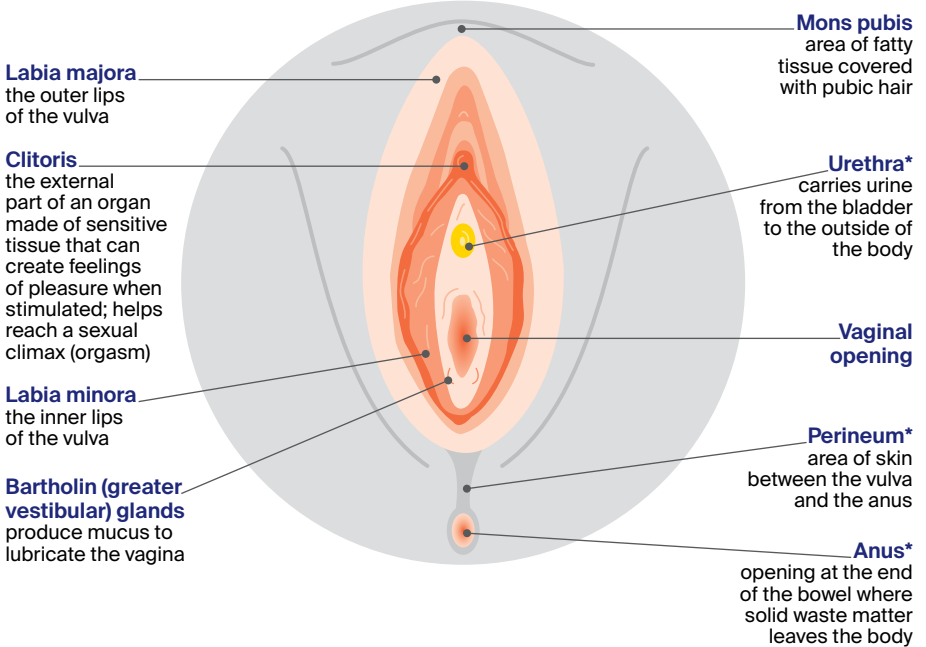
Androgens – These are often called male sex hormones. The major androgen is testosterone, which is produced mostly in the testicles, but also in the male and female adrenal glands. It causes the reproductive organs and other sexual characteristics, such as body/facial hair and a deep voice, to develop. Some cancer treatments (e.g. for prostate cancer) include testosterone-blocking drugs (androgen deprivation therapy or ADT). These drugs can affect the ability to get or keep an erection and reduce your desire for sex. They may also increase body fat, changing your body image, and this can affect how you feel about sex.

The ovaries make small amounts of androgens, which may support female sexual wellbeing. The levels of androgens decrease during and after chemotherapy, and can drop suddenly if the ovaries are removed.

Oestrogen and progesterone – These are often called the female sex hormones. Oestrogen keeps the vagina moist and supple and contributes to feelings of wellbeing and concentration, while progesterone controls reproduction. Both hormones are produced mostly in the ovaries until menopause, when the ovaries stop releasing eggs and periods end. Small amounts of oestrogen and progesterone are made in the adrenal glands before and after menopause. Some cancer treatments can affect these hormone levels, causing early menopause or menopause-like symptoms.

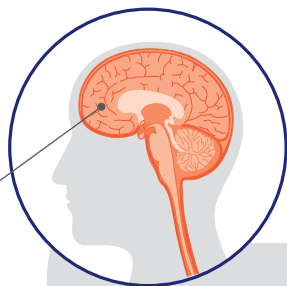
The female sexual and reproductive anatomy

The female sexual and reproductive organs are found inside (internal) and outside (external) the body. You may or may not have some of these organs.



* Not part of the external sexual organs or the reproductive system

Brain
main sexual
organ



Breasts*
sensitive to touch;
erogenous zone

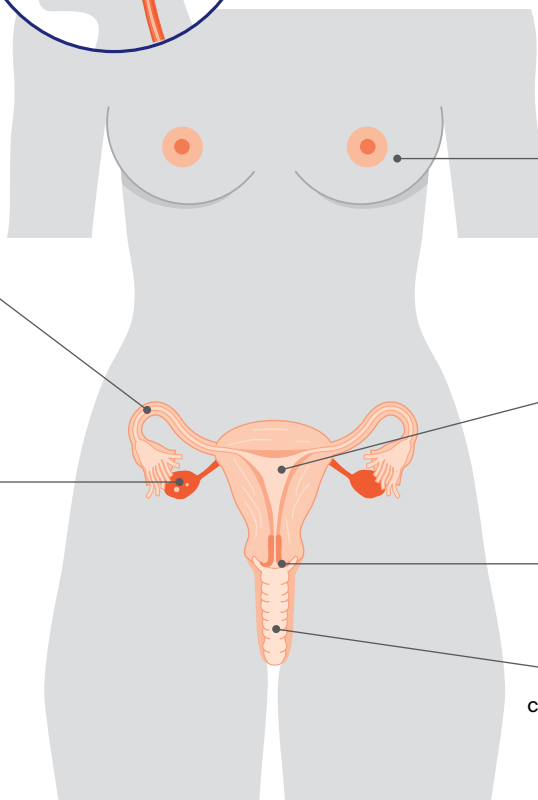
Fallopian tubes
carry sperm to
the eggs, and
carry eggs from
the ovaries
to the uterus

Ovaries
contain eggs
and produce
the hormones
oestrogen and
progesterone,
as well as small
amounts of
androgens

Uterus (womb)
a hollow
muscular organ
where a fertilised
egg (ovum) is
nourished to
form a baby

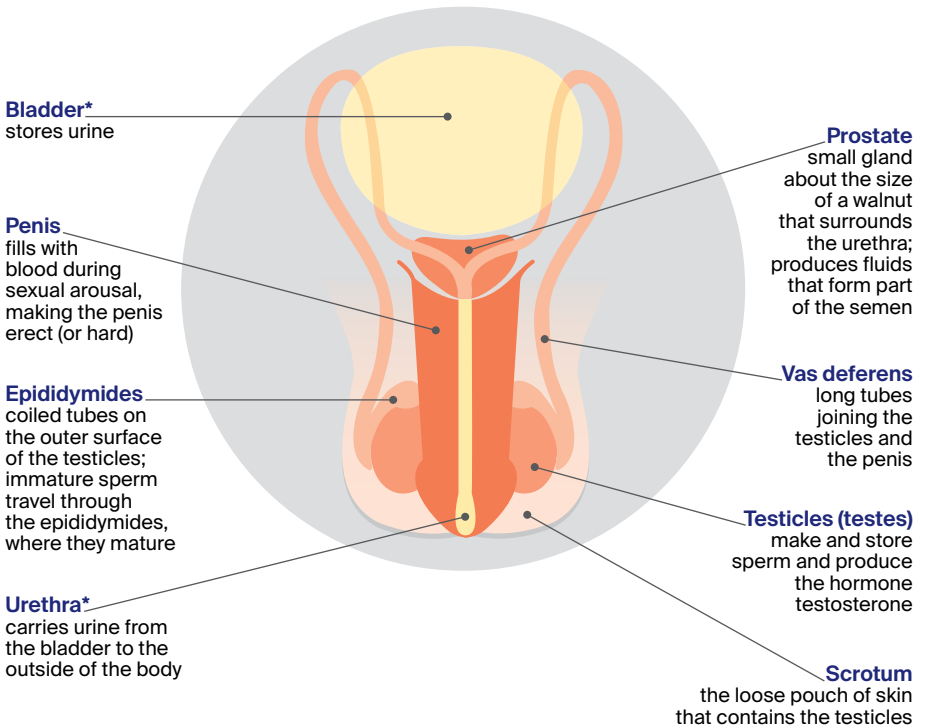
Cervix
the neck
of the uterus

Vagina (birth canal)
a muscular sheath or
canal that extends from
the cervix to the vulva

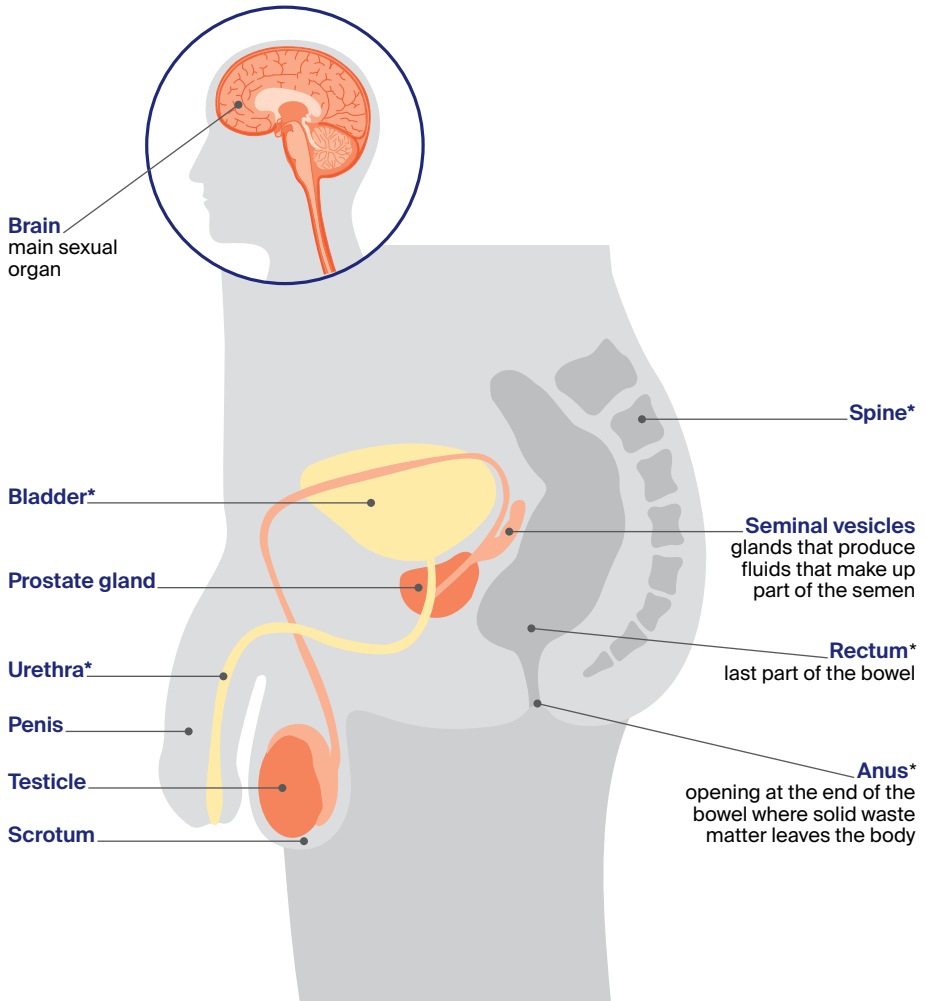


The male sexual and reproductive anatomy

The male sexual and reproductive organs are found both inside (internal) and outside (external) the body. You may or may not have some of these organs.



* Not part of the external sexual organs or the reproductive system





Treatment side effects

The most common treatments for cancer are surgery, radiation therapy, chemotherapy and hormone therapy. Other treatments you may have include immunotherapy and targeted therapy. You may have just one treatment, or a combination of a few. These treatments, as well as the cancer itself, can have temporary or permanent effects on your sexuality by changing:

- your feelings
- the body's production of the hormones needed for sexual response
- the physical ability to give and receive sexual pleasure
- your body image, how you see yourself, and your level of self-esteem
- roles and relationships.

When you are first diagnosed with cancer, it's completely natural to feel a range of emotions. These can include grief, anger, anxiety, sadness, fear, guilt, self-consciousness, shame and depression, which can in turn affect your sexuality.

It's normal to focus mostly just on getting well. As treatment progresses, you may start to notice more effects on your sexuality. These will take some time to adjust to. To help manage specific concerns, see pages 34–62.

Surgery

Any cancer surgery – especially one that creates a scar or removes a body part, such as a breast or testicle – may affect your sense of self and body image. This can affect how you feel about your sexuality. Some surgery in particular may have specific impacts on your sex life:

Hysterectomy – This removes the uterus and sometimes the cervix. A hysterectomy may shorten the top part of the vagina, but doesn't change your ability to have sex. The clitoris and lining of the vagina will remain sensitive, so you will usually be able to feel sexual pleasure and reach orgasm. Because there will be no contractions in the uterus during orgasm, sexual pleasure may be affected for some people.

Orchidectomy or orchiectomy – One or both testicles may be removed. If one testicle is removed, there should be no lasting effect on your sex life or fertility. Your remaining testicle should make enough testosterone and sperm to conceive a child. The scrotum's appearance can be maintained with an artificial testicle (prosthesis, see page 54).

Having both testicles removed (bilateral orchidectomy), which is rarely required, means you will no longer produce sperm. This causes permanent infertility. You can store sperm before the surgery to use later. Your body will also produce less testosterone, which may affect your sex drive, but this can be improved with testosterone replacement therapy.

Penectomy – Part or all of the penis may be removed to treat penile cancer. The part of the penis that remains may still get erect with arousal and may be long enough for penetration. It is sometimes possible to have a penis reconstructed after surgery, but this is still considered experimental and would require another major operation.

Prostatectomy – This removes the prostate. Side effects may include: erection problems (see pages 40–41), not ejaculating semen during climax (dry orgasm, see page 42), semen going backwards into the bladder instead of forwards (retrograde ejaculation, see page 42), leaking urine during sex (see page 50), loss of pleasure (see page 44), pain during orgasm (see pages 48–49) and penile shortening.

Vagina – A small section of the vagina may be removed to treat vaginal cancer. There should be enough vaginal tissue left for penetration. Some people need surgery that removes the whole vagina (vaginectomy). A vaginal reconstruction may be an option, but after surgery scar tissue can form, making intercourse painful and difficult (see pages 45–49).

Vulvectomy – Removing part or all of the vulva will change the look and feel of your genital area. This can affect how you enjoy sex and also your body image. If the clitoris has been removed, it may still be possible to have an orgasm by stimulating other sensitive areas (erogenous zones) of your body. It can take time for you and your partner to adjust to these changes (see pages 43–47 for tips).

Radiation therapy

Radiation therapy (also called radiotherapy) uses a controlled dose of radiation to kill cancer cells or damage them so they cannot grow, multiply or spread. It can be delivered externally or internally.

Side effects often relate to the body part treated, and may include:

- **fatigue** – your body uses a lot of energy dealing with the effects of radiation. Many people feel very tired during and after treatment
- **skin effects** – your skin may be very sensitive or painful to touch
- **loss of appetite** – you may lose your appetite and lose weight
- **hair loss** – you may lose some or all of the hair on your head, face or body. It usually grows back when radiation therapy has finished.



Most people feel upset at having cancer in an intimate area of their body. Visit canceraustralia.gov.au to download a copy of *Intimacy and sexuality for women with gynaecological cancer – starting a conversation* to help you talk with your doctors.

Radiation therapy to the pelvic area – Often used to treat cancer of the bladder, bowel, cervix, ovary, uterus, vulva, prostate or rectum. It's important to talk to your doctor about ways to preserve your fertility, such as egg or sperm storage, before any treatment begins.

Radiation therapy may cause bowel issues or diarrhoea. This is usually temporary, but may be permanent. You may also lose your pubic hair.

The radiation oncologist will try to avoid the ovaries, especially if you haven't been through menopause. If radiation affects the ovaries, they stop producing hormones. This brings on menopause symptoms, and your periods become irregular or stop. Periods may return after treatment, but infertility may be permanent (see pages 60–61).

“I didn't really realise the radiation would affect my sexuality until it happened. I don't think anyone can tell you what the pain, discomfort and exhaustion will do to you.” DONNA

Radiation therapy to the pelvic area can cause short-term inflammation of the vulva and vagina. Scar tissue from treatment can leave the vagina shorter and narrower (vaginal stenosis). These side effects make sexual penetration painful. A vaginal dilator may be useful after treatment (see page 45). Using water-based lubricants and moisturisers can help, and in some cases, oestrogen-based creams will be suggested.

Erectile dysfunction is common after radiation therapy to the pelvis. It usually starts about 6–18 months after treatment and tends to worsen over time. You may ejaculate less semen, which may be slightly discoloured. Not having erections regularly can also lead to penile shortening.

Radiation therapy to the breast or chest – This can cause the skin in this area to become red and dry, or develop a sunburnt look. It usually returns to normal 4–6 weeks after treatment. Radiation therapy to the armpit may increase the risk of lymphoedema in the arm. Some people develop fluid in the breast/chest (seroma) that can last up to 12 months, or in some cases, up to five years. Changes often can't be noticed under clothing. If you're unhappy with how the breast/chest looks, you may be able to have an operation to reduce the size of your other breast.

Radiation therapy to the testicle – Radiation therapy can damage the blood vessels and nerves needed for erections, causing temporary or permanent erectile dysfunction (see pages 40–41). It may also inflame the urethra, so ejaculating may be painful for some weeks. Reduced sperm production is common, and may be temporary or permanent. Even if you're not sure if you want children in the future, it's worth talking to your doctor about storing sperm before treatment.

Protecting your partner during chemotherapy and radiation therapy

You may be advised to use some form of barrier during specific sexual activities to reduce any risk to your partner from treatment and avoid pregnancy. Your doctor will advise how long you need to use this.

Chemotherapy – The drugs may be released into your body fluids, so your doctor will usually suggest using protection. For intercourse, use condoms or female condoms.

For oral sex, use condoms, female condoms or dental dams (latex squares). Wear latex gloves if using hands for penetration. If you have anal sex, use condoms. Ask your doctor or nurse how long you need to use protection.

Internal radiation – Your doctor will usually advise you to avoid sexual contact or use barrier contraception (such as condoms) during treatment.

Chemotherapy

Chemotherapy uses drugs to kill or slow the growth of cancer cells. The drugs are called cytotoxics and they particularly affect fast-growing cells such as cancer cells. Other cells that grow quickly, such as the cells involved in hair growth, can also be damaged.

The side effects of chemotherapy vary depending on the individual and the type and dose of drugs given. Most side effects are short-term and gradually improve once treatment stops, but sometimes chemotherapy causes long-term side effects. Common side effects include fatigue, nausea, vomiting, diarrhoea, constipation, hair loss and mouth ulcers – all of which may affect your self-esteem and desire to have sex.

Sexuality effects – Chemotherapy can also directly affect the hormones linked to libido, but desire for sex usually returns to normal after treatment ends. Some chemotherapy drugs can affect the nerves needed for the penis to become erect, but this is usually temporary.

Fertility changes – Having chemotherapy can lower the levels of hormones produced by the ovaries. This may cause irregular periods – though they often return to normal after treatment. Sometimes chemotherapy can bring on menopause (see pages 58–59). After menopause, you can't fall pregnant naturally. If you think that you may want children one day, talk to your doctor about egg-storing options before you start any treatment. As chemotherapy can cause birth defects, use contraception during treatment to avoid pregnancy.

Chemotherapy drugs may lower the number of sperm produced and their ability to move (motility). This can cause temporary or permanent infertility (see pages 60–61). Talk to your doctor about any sperm preservation options before you start treatment.

Bloating – Chemotherapy for ovarian or bowel cancer can be given as liquid directly into the abdominal cavity (intraperitoneal chemotherapy). This can cause the belly to swell a little, which may affect your body image, but the liquid will drain away after a short time.

Genital effects – Thrush is a common side effect, especially when taking steroids or antibiotics to prevent infection. It can cause vaginal dryness, itching or burning and a whitish discharge (see page 47 for tips on how to manage thrush). Chemotherapy for vulvar cancer can worsen any skin soreness from radiation therapy.

Chemotherapy suppresses the immune system, so viruses can thrive where they might otherwise be controlled. This means that genital warts or herpes flare-ups can occur and people who have never had an outbreak may suddenly have one. Talk to your doctor for more advice.

Hormone therapy

Hormones, which are naturally produced in the body, can cause some cancers to grow. The aim of hormone therapy (also called endocrine therapy or androgen deprivation therapy, ADT) is to lower the amount of hormones the tumour receives. Hormone therapy can be used for a short time or long term to help reduce the size of the tumour and slow down the spread of the cancer.



Hormone therapy for cancer can interact with hormones used by some trans and non-binary people as part of gender affirmation. It may also interact with maintenance hormones taken by intersex people. You may not be able to continue with these hormones during your cancer treatment. This can impact on your body image and sense of self. Talk to your doctor about the options and what they mean for you.

Anti-oestrogen drugs – Drugs such as tamoxifen, goserelin and aromatase inhibitors are used in hormone therapy to treat oestrogen-sensitive cancers. Oestrogen encourages some types of breast cancer to grow, so anti-oestrogen drugs can help to slow cancer growth or stop new breast cancers from forming.

Some people have no side effects from these anti-oestrogen drugs, while others experience symptoms similar to menopause, including vaginal dryness or discharge, pain during intercourse, hot flushes, weight gain, decrease in sex drive and arousal, night sweats, urinary problems and mood swings. You should have regular gynaecological check-ups during and after hormone therapy, as there is a small risk of developing cancer in the lining of the uterus (endometrial cancer) with some drugs.

Androgen deprivation therapy (ADT) – This is a type of hormone therapy that slows the production of testosterone and is used to treat prostate cancer. Side effects include hot flushes and night sweats, weight gain, fatigue and loss of muscle strength, effects on your memory and emotions, breast enlargement and tenderness, loss of bone density (osteoporosis), and increased risk of heart disease and diabetes. When your body is depleted of testosterone, you may find your sex drive decreases, which can also lead to difficulty getting an erection.

Immunotherapy and targeted therapy

Other drug treatments for cancer include immunotherapy and targeted therapy. Immunotherapy uses substances that encourage the body's own natural defences (immune system) to fight cancer. Targeted therapy attacks specific features of cancer cells to stop the cancer growing and spreading.

Side effects for these treatments vary depending on the particular drug that is used, but can include swelling, weight gain, fatigue, pain, and depression, all of which may affect your libido or ability to have sex. Your doctor will explain if you need to use barrier protection, such as condoms, during sex if you are having these treatments.

- ▶ See our *Understanding Immunotherapy* and *Understanding Targeted Therapy* fact sheets.

Palliative treatment

Palliative treatment aims to improve someone's quality of life by managing the symptoms of cancer, without trying to cure the disease. Many people think palliative treatment is only for at the end of life, but it can help at any stage of advanced cancer. As well as slowing the spread of cancer, palliative treatment can relieve pain and manage symptoms.

Many people say that sexuality and intimacy continue to be important to them even when cancer is advanced. It's okay to talk to your health care team about the impact of any treatment on your sex life or your ability to be intimate.

If you have a partner, try to spend intimate or quality time together, rather than as a "patient" and "carer", during palliative treatment. If you are in hospital or hospice care, ask your treatment team if it's possible to use a double bed so you can cuddle and be together. Intimacy can provide comfort and maintain connection during this time. Even if sexual intercourse is no longer possible or desired, you may enjoy physical closeness through touching, massage or simply lying beside each other.

- ▶ See our *Understanding Palliative Care* and *Living with Advanced Cancer* booklets.

Key points about treatment side effects

Main treatments

- The most common cancer treatments are surgery, radiation therapy, chemotherapy and hormone therapy. Other treatments include immunotherapy and targeted therapy.
- It is difficult to predict how treatment will affect your sexuality and intimacy. Changes can be temporary, longer lasting or permanent.

Effects of cancer treatments on sexuality

- The side effects of cancer treatments can lower your libido and arousal, decrease your ability to orgasm, and reduce your desire for sexual intimacy. Side effects can also change how you feel about yourself.
- Surgical removal of a body part can affect your sense of self and your body image.
- Radiation therapy to the pelvic area can affect sexual function and fertility by damaging blood vessels and nerves in, or near, the sexual organs.
- Chemotherapy can have a permanent effect on your hormones and your fertility.
- Side effects of hormone therapy can include erectile dysfunction, fatigue, weight gain, breast tenderness, increased breast tissue, depression and other menopause-like symptoms.
- Side effects of immunotherapy and targeted therapy may include swelling, weight gain, fatigue, pain and depression.
- Even when cancer is advanced, sexuality and intimacy may remain important.
- Discuss any concerns you have with your health care team.



Resuming sexual activity after treatment

While some people find sexual intimacy is the last thing on their mind during treatment, others say they have an increased need for closeness. An intimate connection with a partner can make you feel loved and supported as you come to terms with the impact of cancer. However, cancer can strain relationships, particularly if you had relationship or intimacy problems before the diagnosis.

Sexuality and intimacy after a cancer diagnosis may be different, but this does not mean it will be better or worse. Your preferred sexual positions or activities may become less comfortable temporarily or change over time. It's natural to feel grief at the loss of your previous sex life or desire. To adapt, you may need to try and be more open to exploring different ways to feel sexual pleasure.

Adapting to changes

There are several ways to prepare for sex and intimacy changes during or after cancer treatment:

Talk openly with your partner – Share any concerns you have about having sex or being intimate. Tell them when you are ready to have sex, what level of intimacy and intensity you prefer, if they should do anything differently and how they can help you to feel pleasure. Some people have had a good sex life but have never spoken openly about it before. It can feel like it might be too awkward, and you might be tempted to avoid it, but having these talks can be helpful. Start with an easy topic and build up to the more difficult ones.

Ask your partner how they are feeling – They may be worried about hurting you or appearing too eager. Sometimes people avoid all contact because they don't know how much touch is okay. You can help satisfy your partner by exploring what they want and what you are able to do.

Take it slowly – It may be easier to start with cuddles or a sensual massage, rather than penetrative sex. Talk about this before you start so you both know what the limits are. You can withdraw your consent at any time, even if you have already begun to have sex. Many people find that things often improve with communication, time and practice.

“Max felt he was not the same man after treatment. He would avoid talking and touching. Counselling gave us ways to help express what was really going on.” PAT

Plan ahead – You may need to plan when to have sex because of things like vaginal lubricants, erection devices, incontinence or stomas. Think about the timing of your medicines – some may reduce pain and make you feel more comfortable, or they might make you feel sleepy and not like being intimate.

Explore different ways to have sex – How you used to enjoy having sex may now be more difficult or not possible after cancer treatment. This can be upsetting, but most people can find satisfying new options. Keep an open mind about ways to feel sexual pleasure – you may want to explore different erogenous zones, such as the breasts, ears or thighs; mutual masturbation; oral sex; personal lubricants; vibrators and other sex toys; erotic images and stories; and sexual fantasies.

Focus on other aspects of your relationship – Many relationships do not depend on sex, and you may or may not see sex as being important. Either way, it can be helpful to talk about how you and your partner feel about your sex life, and work out any differences you may have. Spend time together doing other things you both enjoy, which can also bring you closer. That way, sex isn't the only way that you show your affection and share intimacy, and this can take any pressure off your sex life.

Try exploring your sexuality on your own – Touch and masturbation can help you to understand what has changed and what feels good in a way that you have complete control over. You can take your time to explore how your body reacts, without feeling any pressure to “perform” or to keep going if you don't really want to. A vibrator or other sex toys may increase sensation and bring a sense of fun. Once you have begun to feel comfortable with exploring your body, you can show your partner what feels good and works best, what doesn't work and what has changed.

Use relaxation and meditation techniques – Stress and anxiety can make it much harder to feel in the mood for intimacy. Making time for meditation or mindfulness may help you relax and stay in the moment with your partner. There are many free apps and podcasts that can guide you through learning relaxation techniques. Treatment centres often run programs where you can learn to meditate. Cancer Council also has a podcast with meditation and relaxation exercises.

▶ Listen to our *Finding Calm During Cancer* podcast series.

Seek assistance – Talk to any member of your health care team or ask your doctor for a referral to a sexual health physician, sex therapist or psychosexual counsellor to help you find solutions.

What if I identify as LGBTQI+?

It is important to feel that your sexual orientation and gender identity are respected when discussing how treatment will affect you. Your health care team should openly discuss your sexual needs and support you and your partner throughout treatment.

Coming out as LGBTQI+ to your treatment team is a personal choice. It's up to you whether you want to share your sexual orientation, preferred pronouns, sex or gender. It may make it easier for you to discuss your sexual health and for your treatment team to give you the most relevant information or connect you to LGBTQI+ support groups.

You can call Cancer Council 13 11 20 to talk through your concerns and ask for information. Your state or territory Cancer Council may also have LGBTQI+ specific resources on their website (see back cover).

You can contact QLife, a national counselling and referral service for people who are lesbian, gay, bisexual, trans, queer or questioning and/or intersex. Call 1800 184 527 or visit qlife.org.au.

If you have a partner, you can encourage them to come to your appointments. This lets your doctor know who's important to you and will mean your partner can be included in any discussions.

Before your first appointment, it's okay to phone or email your doctor to find out if they are LGBTQI+ friendly. You could ask, "My wife will attend the appointment with me, we are both women, will we be welcome at your clinic?" You can ask your GP to include information about you in their referring letter, such as your sexual orientation, or preferred name and pronouns.

"I was deliberately out as gay to my doctor and nurses. They handled it well, acknowledged my husband, and we use joint decision-making in addressing sexual changes." SIMON

Communicating with your partner

Misunderstandings, different expectations and conflicting ways of dealing with change, can all cause tension within a relationship. The key to adjusting to sexual changes after cancer is communication.

It may help to talk about how you're both feeling, your concerns and your needs, as well as ways you can adapt intimacy and sexual activities during and after cancer treatment. Even people who are comfortable sharing their thoughts with their partner, may not have openly talked about sex before. Common reasons people may avoid talking about sex include: embarrassment; lack of time or privacy; lack of confidence or fear of rejection; fear of getting cancer; waiting for the other person to mention it; and assuming that things are back to normal.

It can seem easier to avoid talking about sex when you are both coping with the demands of cancer and treatment, but this often leads to frustration and confusion, as neither of you will feel like you are having your needs met. Let your partner know what you're going through and how they can help you cope. It may help to talk about how your relationship is changing and that you both need time to adjust.

Sometimes it's better to have these talks outside the bedroom. To avoid any confusion or feelings of pressure, consider talking about sex at a time when you aren't usually going to be having sex.

It can also help to set aside time for other types of intimacy. Plan to have a regular meal together or go for a walk. Try to focus on sensual activities that don't involve penetrative sex, such as hugging, skin-to-skin contact or massage. If you need support talking to each other, consider counselling – call Cancer Council 13 11 20 or ask your doctor or nurse how to find a counsellor in your area.

How to start a conversation about sex

It's hard to know what to say or how to begin a conversation sometimes. Even if these suggestions don't fit your situation, they might give you a starting point.

With your partner

"I feel like I never have any energy for sex, but I'm worried about how you're feeling about that. Maybe we can work out a plan together."

"I am going to show you the way I like to be touched and the places that are sore and out of bounds."

"I feel ready for sex again, but I'd like to take things slowly."

"I'm ready to cuddle, but worried you think I'm ready for sex – can we agree to just cuddle for now?"

"There are some things I would like to try to do together that may help us feel close and connected, without 'going all the way'."

"I really miss our sex life. When can we talk about being physically close again?"

"That's the right spot, but a lighter touch would feel good."

With a new partner

"The cancer treatment changed my body in different ways. It's hard to talk about the changes, but I want you to know about them. The treatment left me with [a stoma/ erection problems/etc.]."

"I really like where our relationship is going. I need you to know that I had cancer some years ago, but I'm afraid you might prefer to be with someone who hasn't had cancer. What are your thoughts about it?"

"I am still interested in sex, but we might have to be a little inventive."

"I haven't had sex since my cancer treatment, and I'm worried about how things will go. How do you feel about taking things slowly?"

"Before we get really serious, I want to let you know how cancer treatment affected my fertility. I can't physically conceive children, but I'm willing to explore other ways of becoming a parent down the track."

Communicating with a new partner

You may be worried about starting a sexual relationship with someone new in the future. It isn't easy to decide when to tell a potential sexual partner about any changes to your body (such as having a breast removed or breast reconstruction, or if you need assistance with erections or have a stoma). It's natural to be worried about their reaction to seeing you naked for the first time. Likewise, you may feel concerned about explaining any issues with fertility, especially if you had cancer when you were young.

Take your time and, when you feel ready, let a new partner know how cancer has changed your body. It may be easier if you practise what you want to say with someone. Think about answers to any questions they may have. Start with small amounts of information and provide further details if they ask. Before any sexual activity, you may want to show the other person how your body has changed, so you can both get used to how it makes you feel.

If you're a young adult

During and after cancer treatment, young people need to continue to develop and mature. This means living as normal a life as possible, which might include going on dates or having a partner. These activities can feel especially challenging if you are dealing with changes to how you look or fertility issues, or if you feel you haven't had much experience of sex with someone.

As well as talking to your treatment team and possibly seeing a sex therapist, you could get in touch with Canteen. They offer counselling in person or over the phone, via email or direct message (DM). Canteen also runs online forums and camps. Call 1800 835 932 or visit canteen.org.au.

Key points about sexuality after treatment

Sexuality and intimacy after treatment

For many people, having a fulfilling sex life after cancer means finding new ways of giving and receiving pleasure.

Adapting to changes

- Talk to your partner about how you are feeling and how things may have changed for you.
 - When you are ready for intimacy, start slowly and take your time.
 - You might need to plan ahead for sex. Choosing the best times and being prepared can help you to cope better with pain, fatigue, body image concerns and other issues.
 - Use masturbation to help you explore how your body has changed and what feels good.
 - If you find that you become distracted during sex, try learning mindfulness and relaxation techniques to help you stay in the moment.
 - Speaking to a counsellor or sex therapist, or to someone who has been in a similar situation, can help you learn ways to adapt to sexual changes.
 - If you identify as LGBTQI+ it is important to feel that your gender identity and sexual orientation are respected by your health care team. You may choose to be open about these things or you may prefer to keep it private.
-

Starting a new relationship

If you are starting a new relationship, it may take time before you feel ready to discuss how cancer has changed your body or the way you have sex.

Overcoming specific challenges

Many of the challenges in this chapter are common for anyone with cancer. Other challenges are less common, or caused only by particular treatments. Some changes are temporary, while others are ongoing.

Fatigue

It's common to feel tired and lack energy during and after cancer treatment. This can continue for weeks or months, and varies from person to person. You may lose interest in sex or need to take a less active role. Your partner may be tired, which can impact their libido.



Tips for managing fatigue

- Regular light to moderate exercise has been shown to reduce fatigue. Even a walk around the block can help. An exercise physiologist or physiotherapist can suggest exercises that are right for you.
 - Plan ahead. Rest before having sex.
 - Use memories and fantasies, or erotic material to spark your interest.
 - Try to be intimate at different times of the day.
 - Speak to an occupational therapist, cancer support nurse or a Cancer Council 13 11 20 consultant about ways to manage fatigue.
 - Spend time being affectionate with your partner – hugging, kissing and holding hands are all ways of feeling close when you're too tired for sex.
- ▶ See our *Fatigue and Cancer* fact sheet or listen to our “Managing Cancer Fatigue” podcast episode.

Anxiety

Feeling anxious and scared is a normal reaction to finding out that you have cancer and going through treatment. Thinking about intimacy or having sex may also make you feel anxious. You may worry about how you look, how your partner will respond or how your body will perform, dread being touched, or fear that sex will be painful. If you're single, you may also feel worried about starting a new relationship.

Anxiety may affect your self-esteem and as a result you may lose interest in sex or find yourself avoiding it. You may feel less anxious if you find out more about your cancer and ask your treatment team what to expect. Think about how you have managed stressful situations in the past, and discuss these strategies with your partner or a trusted family member or friend.



Tips for managing anxiety

- Try mindfulness techniques, relaxation or meditation. Relaxing your body and mind often helps you feel more in control and able to cope with fear, tension and anxiety. Cancer Council has relaxation and meditation tracks available in our *Finding Calm During Cancer* podcast series or as CDs.
- If your thoughts are unhelpful or hard to control, consider cognitive behaviour therapy (CBT). This can show you how to change thought patterns that might be getting in the way of a fulfilling sex life. A psychologist or counsellor can help. Ask your GP for a referral – you may be eligible for a Medicare rebate.
- Share your thoughts with your partner. It shows trust and helps create intimacy.
- Talk to your doctor about whether medicine may help manage your anxiety. However, some medicines may lower your libido.

How to deal with feelings of sadness and depression

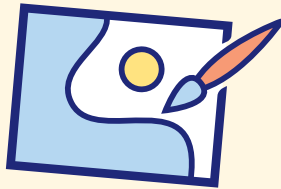
It's natural to feel down during any stage of a cancer diagnosis. Changes to your body can be upsetting and it takes time to adjust. Some medicines and treatments can also affect your mood. Simple daily habits and the tips below

Aim for a good night's sleep



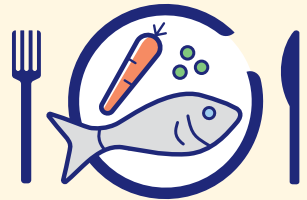
Poor sleep can make depression worse, so try to get up and go to bed at the same time each day. Avoid long naps or caffeine after lunchtime. In the evening, swap screen-time – watching TV or using your phone/tablet – for relaxation exercises. If you wake to go to the toilet a lot, try drinking less at night or ask your doctor if there is anything that can help.

Add an activity to your day



Getting back into activities can lift your mood. You could make a list of things you enjoyed before cancer and try one a day. Plan a time for hobbies or talking to friends, instead of waiting until you feel “up to it”. You may need to adapt – if you can't manage a book, try an audiobook. Focus on things that make you feel good (a fun movie), or in control (finishing a job you put off). Break tasks into steps if you feel overwhelmed. If you don't get to it today, try again tomorrow.

Eat a balanced diet



Nutritious food can help to improve your energy levels, sexuality and sleeping patterns. If you find that you don't feel like eating anything, try a small snack until your appetite returns. Try to drink enough fluids to stay hydrated – tea, water and low-sugar juices are good choices. Try to eat mostly healthy options with the odd treat.

may help improve how you feel. Sometimes feelings of sadness become very strong, and start to affect other parts of your life, including sexuality. Talk to your treatment team if you are feeling more low than usual or if it persists.

Try regular exercise



Physical activity can help improve your mood, so be active if possible. Plan some exercise each day, but be kind to yourself if you can't make it. Start slowly – if you can't go for a walk, just be outside. Begin moving around, even if you're not in the mood. You can always stop if you don't feel up to it. A massage (if appropriate for your cancer type) may help you feel like being active again.

Ask about medicines



Depression is common if you have low levels of sex hormones or hormone changes. Ask your doctor if your medicine or treatment could also affect your mood, sleep or libido. If you have continued feelings of depression, talk to your doctor, as counselling or medicines – even for a short time – may help. Let them know if sex is important, as some antidepressants can affect sexual function.

Where to get more help



If you worry that you, or someone you care for, may be depressed, you'll find a checklist and helpful information by calling 1300 22 4636 or visiting beyondblue.org.au. For 24-hour crisis support, call Lifeline 13 11 14 or visit lifeline.org.au. You can also talk to your GP or your cancer care team. In an emergency call Triple Zero (000) or go to an emergency department.

Loss of desire

While loss of desire may not be a problem for some people, changes in sex drive or interest (low libido) are common during cancer treatment.

There are many reasons why your libido might change, including:

- treatment side effects such as feeling tired and sick
- pain when recovering from surgery
- being too worried about the cancer to think about sex
- fear of pain during penetrative sex
- changes in your hormone levels
- loss of confidence and self-esteem as treatment may have changed the way you look.

Most people find that their libido returns when treatment ends, but keep in mind that hormone levels also change with age, and you may notice a gradual decrease in your sex drive as you get older.

Adjusting to changes in sex drive can be emotionally and physically challenging for people with cancer. Discuss the changes with your partner, so they can understand instead of feeling rejected.

If you feel you need further support or ideas on how to help your relationship get through this stressful time, consider talking to a counsellor, sexual health physician or sex therapist. Speak to your doctor for contacts in your local area or call Cancer Council 13 11 20.

“My wife went off sex completely during her treatment, which was difficult for me. When we talked about it, and she told me she still loved me, it made me feel better.” DAVID



Tips for when your libido is low

- Make it a priority to spend time with your partner. Arrange a “date” or even a weekend away.
- Enjoy physical contact without sexual penetration to maintain intimacy. Try skin-to-skin touch, such as massaging each other, or having a bath together.
- Suggest a quick, gentle lovemaking session rather than a long session.
- Keep an open mind. You could read an erotic story, watch an erotic movie or try some adult products (e.g. personal lubricants and sex toys like vibrators). These may help spark your interest in sex or your partner can masturbate, either alone or with you present.
- Stimulate yourself so you become aware of how you like to be touched.
- Change the venue. If you and your partner have been coping with the side effects of treatment at home, book a night away or try using rooms in the house that are not associated with cancer.
- If your usual sexual positions have become uncomfortable, experiment with different ones to find something that feels better.
- Use cushions or pillows to support your weight.
- Rearrange the bedroom furniture or think about redecorating once your treatment is over.
- Ask your doctor about having a hormonal assessment to check your hormone levels.
- Try different ways of getting in the mood for intimacy: wear clothes that make you feel sensual, light candles and play soothing music, shower or bathe together, share erotic images or stories, or have a weekend away if you can – whatever makes you feel sexy, relaxed and good about each other.

Ways to improve erections

There are several options for trying to improve the quality of your erections, regardless of the type of cancer treatment you have had.

Tablets



There are medicines used to increase blood flow to the penis. These only help if the nerves controlling erections are working. These tablets should not be taken with some blood pressure medicines. Check with your doctor if these could be suitable for you.

Your doctor may recommend using the tablets before and soon after surgery, as the increased blood flow can help preserve penis health until the nerves recover. Tablets are also an option after radiation therapy and ADT.

Vacuum erection device (VED)



A VED or “penis pump” uses suction to make blood flow into the penis. This device can also help to strengthen or maintain a natural erection. You place a clear, rigid tube over the penis. A battery-operated or manual pump then creates a vacuum that causes blood to flow into the penis so it gets hard. You place a rubber ring at the base of the penis to keep the erection firm for intercourse after the pump is removed. The ring can be worn comfortably for 30 minutes.

Talk to your doctor about suitable devices for you and where to buy them.



You may see or hear ads for ways to treat erection problems. These ads may be for herbal preparations, natural therapies, nasal sprays and lozenges. If you are thinking about using these products, talk to your doctor first, as there could be risks without any benefits. Products that contain testosterone or act like testosterone in the body may encourage some cancers to grow.

Ask your treatment team for more details about these methods and other things you can do to get erections firm enough for penetration.

Penile injection therapy (PIT)



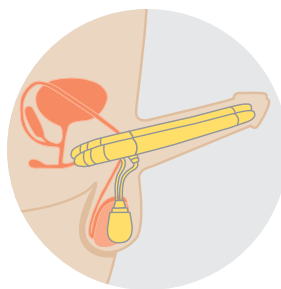
PIT involves injecting the penis with medicine that makes blood vessels in the penis expand and fill with blood, creating an erection. This usually occurs within 15 minutes and lasts for 30–60 minutes.

The medicine has to be prescribed by a doctor. It often comes in pre-loaded syringes, which are single use. You can also buy it in vials from a compounding pharmacy and measure it out into a syringe yourself.

You will be taught how to inject the penis. Injecting your penis may sound unpleasant, but many people say it causes only a moment of discomfort.

PIT works well for many people, but a few may have pain and scarring. A rare side effect is a prolonged and painful erection (known as priapism). This needs emergency medical attention.

Implants



A penile prosthesis is a permanent implant that allows you to create an erection. Flexible rods or thin, inflatable cylinders are placed in the penis during surgery and connected to a pump in the scrotum. You turn on or squeeze the pump when you want an erection.

It is usually recommended to wait at least a year after most cancer treatments before having an implant. Non-surgical options such as oral medicines or injections will usually be tried first.

Occasionally, penile implants need to be removed. If this happens, you will no longer be able to have an erection.

Changes in ejaculation

After surgery for prostate cancer, you will not produce semen. This means that you will have a dry orgasm, which can feel quite different – some people say it does not feel as strong or long-lasting as an orgasm with semen, while others say it is more intense. Sometimes surgery causes semen to go backwards into the bladder, rather than forwards out of the penis. This is called retrograde ejaculation. This is not dangerous or harmful, but it does mean you will be infertile.

In some cases after prostate surgery, you may leak a small amount of urine during ejaculation (this is not harmful). If you are feeling anxious about your sex life, premature ejaculation can also be a problem.



Tips for adapting to ejaculation changes

- Discuss the changes with your partner and reassure them that it doesn't affect your enjoyment of sex. Include lots of foreplay to increase your satisfaction.
- Empty your bladder (urinate) before sex to minimise urine leakage. If you or your partner are worried, you can use a condom or constriction ring (available from sex shops) at the base of the penis to catch any leakage. Pelvic floor exercises (see page 51) can help improve bladder control.
- Ask your doctor about medicines or numbing gels, or talk to a sex therapist about the stop-start technique.
- Focus on enjoying sexual activity. Worrying about controlling your ejaculation may lead to erection problems or loss of interest in sex. Consider counselling to help ease your anxiety.

Difficulty reaching orgasm

If you've had your clitoris or other sensitive areas of the vulva removed, you may have difficulty reaching orgasm. Removal of the uterus, cervix and ovaries can also change how you experience sexual pleasure and orgasm.

Worrying about cancer or cancer treatment can make reaching an orgasm more difficult.

As the brain is one of the major sexual organs, thinking about past sexual experiences or fantasies can sometimes help. You could try exploring erotic stories in books, magazines or in film.



Tips for reaching orgasm

- Use masturbation to see what works for you.
- Use stroking and massage, or guide your partner's hands or fingers to areas that arouse and excite you.
- Focus on your breathing. Try to tense and relax your vaginal and pelvic floor muscles in time with your breathing during penetration or while your clitoris is being stroked.
- Explore reaching orgasm without penetration. Try oral sex, masturbation with sex toys or all-over touching.
- Try different positions: experiment with tensing your thighs, closing or opening your legs or pointing your toes.
- Consider using an electric vibrator, which may give you the extra stimulation you need to reach orgasm.

Loss of sexual pleasure

During and after cancer treatment, some people find that even though they can still have sex, they don't enjoy it as much. This may be for emotional reasons, such as worrying or self-consciousness, or from a physical cause, such as fatigue, nerve damage or painful intercourse. As side effects improve, many people start to enjoy sex again. If you had your breast or prostate removed, you may need to explore touch and stimulation to other parts of the body to feel ready for sex.



Tips for more enjoyable sex

- Consider agreeing to just touching, hugging and kissing. This is a chance to feel close to your partner and relax knowing there's no expectation of sex.
- Choose a time when you won't be disturbed, and set a calming peaceful atmosphere.
- Place your partner's hands and fingers on the areas that arouse and excite you – or touch those areas yourself.
- Change your normal positions to more comfortable ones that increase stimulation.
- If you are having difficulty reaching orgasm, see the tips on the previous page.
- Try using a personal lubricant with a water base. Avoid warming gels or lubricants with perfumes or flavours added, which may irritate delicate tissue or sensitive areas.
- Accept that you may not reach orgasm every time. Take the pressure off by focusing on giving and receiving pleasure in different ways, not reaching a certain point.
- Learn mindfulness to help you stay in the moment with your partner. Listen to Cancer Council's relaxation and meditation tracks, available in our *Finding Calm During Cancer* podcast series or as CDs.

Changes to the vagina

Cancer treatments may cause temporary or permanent vaginal changes. Surgery may shorten the vagina, and pelvic radiation therapy can narrow the vagina, causing thinning of the walls and dryness. Penetration may become difficult and painful. A vaginal dilator may help (see below).

Some people experience tight vaginal muscles (vaginismus) after cancer treatment. This is often caused by fear of painful penetration. Ask your health care team for a referral to a pelvic health physiotherapist, who can help you learn how to relax the pelvic muscles during penetration.

After cancer treatment, you may need vaginal moisturisers and lubricants to avoid discomfort during penetration (see next 2 pages).

Using vaginal dilators



A vaginal dilator can help keep your vagina open after treatment. A tube-shaped device made from plastic or silicone, the dilator is inserted into the vagina for short periods of time to gradually widen the entrance and prevent the walls sticking together. Dilators come in a range of sizes.

You usually start with a short and thin one and "work up to" a longer, wider one over a period of time. It's important to use dilators regularly for them to work. Vaginal dilators are not for everyone and they can be painful. If you don't have penetrative sex, you may not worry about using one. Talk to your doctor about the benefits – for some people it's worth it, and for others it may not be. Ask your health care team for a referral to a pelvic health physiotherapist. You can call Cancer Council 13 11 20 and ask to speak to someone who has used a vaginal dilator before.

How to cope with changes to the vagina

Some cancer treatments can change the size of the vagina and make sex uncomfortable or painful. A lack of oestrogen from some cancer treatments

Short/narrow vagina

- Use personal lubricant to make penetration comfortable. Choose a water-based or silicone-based gel without added perfumes or colouring.
- Ask your nurse or doctor about a non-hormonal vaginal moisturiser and apply several times a week to help keep your vagina lubricated.
- Try a vibrator or regular, gentle sexual intercourse. Experiment with positions for penetration.
- Use a foam ring around the base of your partner's penis to reduce discomfort and pain during intercourse.
- Talk to your doctor about whether to use a vaginal dilator (see previous page) to widen your vagina after you've finished radiation therapy.

Vaginal dryness

- Avoid soap, bubble bath and creams that can irritate your genitals.
- Try a vaginal moisturiser. This non-hormonal, over-the-counter product can help restore lubrication and the natural pH level of the vagina and vulva. It is usually applied 2–3 times per week at night.
- Talk to your doctor about whether oestrogen creams or pessaries (tablets put into the vagina) are an option for you. They may not be right if you are having hormone therapy for cancer. Oestrogen creams are applied in the vagina or onto the vulva, and can help relieve discomfort.
- Personal lubricants are liquids or gels that are applied around the clitoris, labia and vaginal entrance, as well as your partner's penis during sex. Try applying lubricant as part of your sexual foreplay. Lubricants with a silicone base may last longer than the water-based ones. Avoid oil or petroleum-based products (e.g. baby oil or Vaseline) as they can increase the chance of vaginal infection and damage latex condoms.
- To improve sexual arousal, take more time before and during penetration to help the vagina relax and become well lubricated.

can cause vaginal dryness, which may lead to thrush. Treatments such as radiation therapy may cause a loss of sensation in the vagina.

Thrush

- Thrush can occur when genital dryness causes an overgrowth of a yeast-like fungus that is commonly found in the vagina. It can cause itching, burning and an unpleasant discharge, and may make intercourse painful.
- Seek medical advice to rule out other types of vaginal infections.
- Treat thrush with prescription creams or medicines.
- Wear loose, cotton clothes. Avoid nylon pantyhose, tight jeans or pants.
- Don't use petroleum-based products (e.g. Vaseline) as a lubricant.
- Use a condom to avoid spreading thrush to your partner during sex.
- Ask a dietitian about what to eat to help control thrush. They may suggest eating foods low in sugar and yeast.

Loss of sensation

- Some women experience a loss of sensation in the vagina or labia which may be temporary or permanent, depending on the type of treatment they have had. This can make sex uncomfortable or unsatisfying, or may cause low libido and arousal.
- Focus on other areas of your body and genitals that feel pleasurable when touched.
- Try regular sexual activity of some kind to help maintain your interest in sex.
- Experiment with different sexual positions to try and find one that improves sensation.
- Use a vibrator to enhance sensation in the vagina and surrounding area.
- Seek medical advice – some women may benefit from a vaginal examination to identify and treat medical conditions such as thrush.
- If your usual contraceptive device or medicine is irritating you, try different types of contraception.

Pain

After surgery you may feel sore for several weeks, or longer in some cases. You may find it uncomfortable to be touched or hugged if the wounds from the surgery are still healing or if the area around the scar is painful. Pain can reduce your interest and pleasure in sex, and distract you from reaching orgasm. It may also mean the positions you used to have sex in are now uncomfortable. Some pain medicines may make you feel drowsy and tired, which may also affect your libido.

Painful intercourse

In the female body – Pelvic surgery, radiation therapy or treatment that affects hormones can reduce the size or moistness of the vagina, which can lead to painful intercourse. Some people experience vaginismus, when the muscles around the vagina tighten on penetration. This is an unconscious response and often caused by fear that intercourse will be painful. It's important not to push on or persist through the pain as this can often makes things worse. Ask your health care team for a referral to a pelvic health physiotherapist. They can teach you how to keep your muscles relaxed during intercourse.

In the male body – Scar tissue in the penis after surgery can cause pain or bleeding, but it usually settles down in time. Irritation of the prostate or urethra from surgery or radiation therapy can cause painful orgasms. Anal sex can be painful after radiation treatment for prostate or anal cancer. Consider other ways to be intimate, such as oral sex.

“After my big operation I had quite a bit of pain and I would just basically either take the pain medication that they give you, or try and get into a comfortable position with the pillows around you.” ANNAMAREE

Tips for managing pain

Managing pain during sex

- Plan sexual activity for the time of day when your pain is lowest. If you are using pain medicine, take it before sex (an hour before) so it will have maximum effect.
- Try different positions (such as side by side) until you find one that may be more comfortable for both of you and reduces pressure on painful areas.
- Use pillows or cushions to help you feel more comfortable and reduce pressure on a sore area.
- Try relaxation techniques such as a warm bath or massage before having sex.
- If pain continues, you can ask to be referred to a specialist pain clinic. It is important to deal with pain as early as possible, as a holistic approach is best for long-term benefits.
- ▶ See our *Understanding Cancer Pain* booklet and listen to our “Managing Cancer Pain” podcast episode.

Making penetrative sex more comfortable

- Avoid deep pelvic thrusts – choose alternative positions where you can control the depth of penetration.
- Use plenty of lubricant. A water-based lubricant is easier to wash away but a silicone-based one will last longer. Talk to your health care team about which is best for you.
- Try to be close to orgasm or very aroused before penetration.
- Talk to a doctor or sex therapist if these methods don't work. A women's pelvic health physiotherapist may be able to advise on the use of vaginal dilators (see page 45) and pelvic floor exercises to help manage painful intercourse. While using vaginal dilators can be challenging, they can usually offer improvement long-term.
- Ask an occupational therapist what products can help with positioning during sex – they may suggest using wedges, pillows, electric beds or transfer boards.
- If pain is ongoing, ask to be referred to a specialist pain clinic.

Incontinence

Trouble controlling the flow of urine (urinary incontinence) or flow of faeces (faecal incontinence) is a common side effect of treatment for cancer of the prostate, bladder, bowel and penis, or of the female reproductive organs. Incontinence may be temporary or permanent. The pelvic floor muscles that affect bladder and bowel control also affect sexual function and arousal. Having bladder or bowel issues can be embarrassing and impact your sexuality, but there are ways to manage symptoms. For advice on incontinence, call the National Continence Helpline on 1800 33 00 66 or visit continence.org.au.



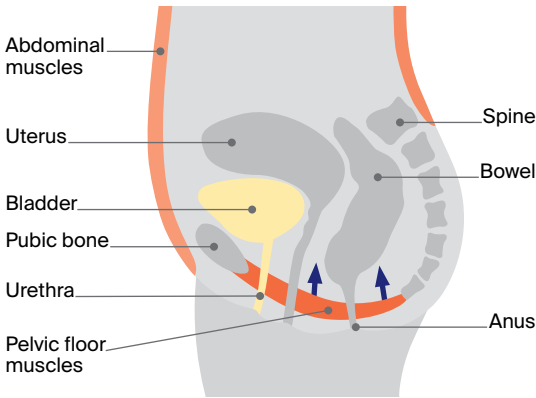
Tips for managing bladder and bowel issues

- Let your partner know that incontinence may occur.
- Cover your bed with large, fluffy towels or have sex in a wet area like the shower.
- If you have a catheter for draining urine, tape the tube to your skin, remove the bag and insert a flow valve or stopper before sex. For a catheter from a penis, fold the catheter back against the penis and put a condom on top to hold it in place.
- If you've had your prostate removed, try having sex in the missionary position with you on the bottom and your partner on top.
- Talk to a continence nurse about plugs for rectal use if you have faecal leakage.
- Learn how to exercise your pelvic floor muscles. See opposite page for a guide.
- Wait at least 2–3 hours after a meal, and empty both the bowel and bladder before having sex.
- Try positions that reduce pressure on the bladder such as being “on top”.
- See a pelvic health physiotherapist for advice. Ask your GP for a referral.

How to exercise your pelvic floor muscles

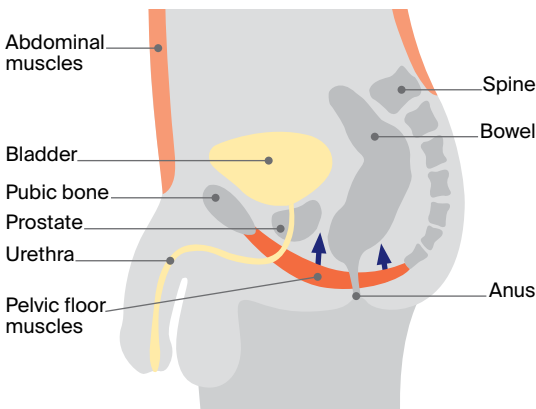
To identify your pelvic floor muscles, try stopping your urine stream for a couple of seconds while emptying your bladder. You use your pelvic floor muscles to do this. Pelvic floor exercises should be done several times a day. The technique is the same for males and females.

Female



1. Start by relaxing all of your pelvic floor and tummy (abdominal) muscles.
2. Gently lift your pelvic floor muscles up and hold while you continue breathing normally. Keep your upper abdominal muscles relaxed. Try to hold the contraction for up to 10 seconds. Relax your muscles slowly after each hold.

Male



3. Repeat the exercise up to 10 times, with a rest of 10–20 seconds between contractions. Relax your pelvic floor muscles completely during the rest periods.

Changes in appearance

If the way your body looks has changed after cancer treatment, you may feel self-conscious. It's common to feel a range of emotions about the physical changes caused by treatment, which may include: changes to body functions; removal of a body part and use of a prosthesis (see pages 54–55); having a stoma (see page 56); loss of hair from the head and body; weight loss or weight gain; skin rashes; swelling of part of the body (lymphoedema); and scars.

Some cancers of the head and neck can cause significant changes to what you look like, how you speak and how you eat or breathe. This can be upsetting because the change is visible, and kissing, speech and eating may be affected.

The way you look may affect how you feel about yourself. Changes to your face or body may make you feel less attractive, and this can affect your sexual confidence, self-esteem and body image. Often people find that their partner (or a potential partner) isn't as concerned about these changes as they are. You may worry about other people's reactions to you, or worry that they will avoid or reject you when they see how your body has changed.

It takes time to adjust to changes in appearance. Some physical changes may improve with time, while others may be more long-lasting. Focus on yourself as a whole person and not just the part that has changed.

Look Good Feel Better program

This free 2-hour program teaches adults and teens how to use skin care, hats and wigs to help restore appearance and self-esteem during and after treatment. Visit lgfb.org.au to book into a workshop. They can also send you a confidence kit if you can't attend in person.



Tips for adjusting to appearance changes

- Remember that sexual attraction is based on a mix of emotional and physical factors, not on a body part or physical characteristic.
- Look and touch your scars to get used to the changes.
- Use clothing, make-up or accessories that make you feel good or highlight your favourite features.
- Consider showing your partner any body changes before sex – and talk through what feels okay. Having your partner look at and touch these areas may help both of you get more comfortable with the changes.
- If you feel uncomfortable about a part of your body, you can wear clothes to cover it during sex – e.g. if you have had breast surgery you may choose to wear a camisole. You may also prefer to avoid sexual positions that leave the area exposed.
- Look at and touch your scars so you get used to the changes.
- Dim the lights or light candles when you have sex until you feel more confident about your body.
- If your hair has fallen out, you can wear a hat, wig or scarf, or you may prefer to leave your head uncovered. See our *Hair Loss* fact sheet or call 13 11 20 for a wig service in your area.
- If you have concerns about weight loss or gain, choose well-fitting clothes. Something too tight or too baggy may highlight weight changes. Consider treating yourself to a new outfit that makes you feel comfortable.
- Ask your doctor about the possibility of plastic surgery or a facial prosthesis if surgery or radiation therapy has affected your face. This may help you regain a more natural appearance and help with any changes in the way you speak.
- See a counsellor to help you adjust to the changes.

Removal of a body part

If your cancer treatment involved the removal of a limb, breast or part of your genitals, it can cause feelings of grief, loss and anger. This can affect your sexual desire and your sexual confidence. It takes time to get used to how your body has changed and how that makes you feel. Try to remind yourself that you are loved for who you are, not for your particular body parts. For suggestions on restoring body image, see the previous 2 pages. Talking to a psychologist or counsellor may help you improve your sex life and relationship, and ease distress after surgery.

Breast – Nipple and breast sensation usually stay the same after breast-conserving surgery, but may change after mastectomy. This can affect sexual arousal if you like being touched on the breast. The surgery may make you feel self-conscious or like you've lost a part of your identity.

Prostheses – People who've had a breast or testicle removed may use a prosthesis to improve self-esteem. This is a personal decision and not something everyone wants. Your specialist can give you more information about your options and what the procedure involves.

Anus – The removal of the anus is a major change, particularly if you have anal sex. It is a key erogenous zone for many people, and though some sex acts may not be possible, you can express intimacy through oral sex, cuddling and stroking. Penetration of the stoma (the opening created to remove waste after surgery) is not an option - it can cause serious physical harm and infections can be passed through the stoma.

Prostate – If the prostate is removed to treat prostate cancer, it can affect sexual pleasure when receiving anal penetration. For support, visit the Prostate Cancer Foundation of Australia at prostate.org.au and see *Understanding prostate cancer for LGBTIQ+ people*.



Tips for sex and intimacy after the removal of a body part

- Look at yourself naked in the mirror to get used to the changes to your body, or use a handheld mirror to see the genital area.
- Show your partner the changes. If it feels okay, teach them how to touch the area in a way that feels nice.
- Accept that it may take time to feel comfortable about your body again.
- If you have had one or both breasts removed, see our *Breast Prostheses and Reconstruction* booklet.
- Touch your genitals to work out how your response has changed and what feels good. Explore other areas of your body that make you feel aroused when touched. This may take time and practice.
- If you are worried about the reaction of your partner (or a potential partner), remember that good communication will help. Sharing your concerns and keeping an open mind will help you explore new ways to be intimate.
- Ask your partner to stroke different areas of your body if your usual erogenous zone has been affected. This may include kissing and touching your neck, ears, inner thighs and genital area.
- If you've had a limb removed, try wearing your limb prosthesis during sex. If you prefer to take off the prosthesis, use pillows to support the affected limb.
- Call Cancer Council 13 11 20 to talk to someone neutral about your feelings.
- Register for a Look Good Feel Better workshop (see page 52). Call 1800 650 960 or visit lgfb.org.au.
- Talk to a sexual health physician, psychosexual counsellor or sexual therapist about the ways any change to your body may be affecting your relationship and sex life. Visit societyaustraliansexologists.org.au to find an accredited sexologist near you.

Adapting to life with a stoma

Some types of surgery for bowel, anal or bladder cancer create a stoma – an opening in the abdomen that allows faeces (poo) or urine (pee or wee) to flow through and be collected in a small plastic bag. Sometimes a stoma is needed for only a short time, but in other cases it is permanent.

Having a stoma can affect your confidence and self-image, though a stoma often causes more embarrassment and distress to the person with a stoma than their partner. Getting used to looking after the stoma will help you feel more confident. Sexual activity for people with a stoma may need a little more planning but can still be satisfying and fulfilling.



Tips for sex if you have a stoma

- Change the bag and check the seal before having sex. This may help with worries about leaking.
- If you prefer, cover your bag with fabric or fold it in half and cover with a cummerbund to prevent the plastic clinging to your skin or the bag from flopping around. This can also help to keep it out of sight if that is a concern.
- Wear clothing that makes you feel good, such as a mini-slip, short nightgown or nightshirt, specially designed underwear or boxer shorts.
- Try sex in the bath/shower.
- After a heavy meal, wait for 2–3 hours before having sex.
- Talk to your stomal therapy nurse about learning irrigation to allow you to use a stoma cap or a small pouch (a “mini”) during sex.
- Use pouch deodorants or wear perfume to help control any odours.
- Allow your partner to see or touch the stoma.
- Contact a stoma association for support. Find one near you at australianstoma.com.au.

Adapting to life after a brain tumour

As brain tumours do not affect sexual organs, you may not expect sexuality to change. However the brain is responsible for sexual urges, thoughts and behaviours.

The areas most commonly involved in sexual functioning include the frontal, temporal and parietal lobe, and pituitary gland. When these parts are injured, it can cause problems with behaviour, thinking and memory, personality and social skills.

Possible changes in sexuality after a brain tumour include:

- loss of libido or sexual drive (see pages 38–39, and 44)
- having an increased desire for sex (hypersexual)
- inability to achieve or maintain an erection (see pages 40–41)
- difficulty or inability to orgasm (see pages 42–43)
- premature ejaculation
- talking a lot about sex or inappropriate touching (disinhibition)
- weakness in an arm or leg, or slow and uncoordinated movements
- fatigue (see page 34)
- changes in self-image and relationships (see pages 52–53 and 63–64).

If you have become uninhibited or hypersexual after surgery, your family and friends may ask you to masturbate in private and not to make sexual comments. For help following brain cancer, call Cancer Council on 13 11 20 or visit buildingthebridge.com.au.

“The most distressing time for me was immediately post op when my side effects were many, varied and quite severe, even though most turned out to be temporary.” IAN

Early menopause

Natural menopause occurs when your ovaries stop working and you no longer menstruate (have periods). This means you will not be able to fall pregnant naturally. For most people, this usually happens between 45 and 55.

Most menopause symptoms are related to a drop in your body's oestrogen levels. Symptoms may include aching joints, mood changes, hot flushes, night sweats, trouble sleeping, a dry vagina, reduced libido, dry or itchy skin, increased urinary frequency and "fuzzy" thinking. However, some people have few or minor symptoms.

Early menopause (premature ovarian insufficiency or POI) is the term for menopause that occurs before the age of 40. When this happens because of cancer treatment, it may be called induced menopause. When menopause starts suddenly, the symptoms are usually more severe than natural menopause because your body hasn't had time to get used to the gradual loss of hormones. Premature menopause may also cause bones to weaken (called osteoporosis or osteopenia).

Going through menopause earlier than you expected may affect your sense of identity, or make you feel older than your age or friends. You may feel less feminine, and worry that you are not as attractive. For some people, not having periods is a positive.

Many kinds of cancer treatments can result in menopause symptoms or early menopause. These treatments include: surgery in which both of your ovaries are removed; hormone therapy to decrease your body's production of oestrogen; and radiation therapy and chemotherapy, which may affect your ovaries' ability to produce eggs and hormones.

If your uterus is removed (hysterectomy) you will no longer have monthly periods or be able to carry a child. However, if you still have at least one ovary, you will continue to produce oestrogen – which means you will go through natural menopause at the normal stage of life. If both of your ovaries and/or your uterus are removed, your periods will stop and you will experience a surgical menopause.

See pages 60–61 for information about fertility issues. See also *How to cope with changes to the vagina* on pages 46–47 for tips on coping with a dry vagina caused by menopause.



Tips for managing menopause symptoms

- If cancer treatment causes early menopause, consider seeing a menopause clinic to discuss the options for managing symptoms.
- Identify and avoid things that trigger hot flushes, such as alcohol, hot drinks, spicy foods or anxiety.
- Learn meditation and relaxation techniques, and exercise regularly to reduce stress and symptoms.
- Try topical hormone treatments, such as vaginal creams, to manage symptoms. There are also non-hormonal options, such as acupuncture.
- Talk to your doctor about the benefits and risks of menopause hormone therapy (MHT) for severe menopause symptoms.
- Ask your GP to arrange a bone density test to check for osteoporosis or osteopenia, which can develop after menopause.
- Try to eat high-calcium foods, talk to your doctor about a supplement, and exercise regularly to strengthen your bones and reduce bone loss. Call Healthy Bones Australia on 1800 242 141 or visit healthybonesaustralia.org.au for more information.

Fertility issues

Some cancer treatments can cause infertility (difficulty conceiving a baby), which can be temporary or permanent. If fertility is important to you, talk to your doctor before your treatment starts about the risks and your options. It may be possible to store your eggs, embryos, ovarian tissue or sperm for use in the future.

When people learn that they may be permanently infertile, they often feel a great sense of loss. You may be devastated that you won't have your own children or have more children, and you may worry about the impact of this on your relationships. Even if your family is complete or you didn't want children, you may experience strong emotions. This can change how you feel about yourself as a sexual being and affect your sexuality.

As well as talking with your partner, it may help to talk with a counsellor, sex therapist, your GP or your cancer treatment team.

▶ See our *Fertility and Cancer* booklet.

If female reproductive organs are affected – Surgery that removes part or all of the reproductive organs, such as the ovaries, fallopian tubes, uterus and cervix, will cause your periods to stop and you will be unable to conceive a child.

Depending on the type of chemotherapy drugs used and the dose, periods may become irregular but they often return after treatment ends. In some cases, periods stop permanently, leading to menopause.

If sperm production is affected – Surgery for bladder, prostate or testicular cancer may damage the nerves for getting and keeping an erection. This may be temporary, but some people may not get strong

erections again, or have permanent erection issues (see pages 40-41). If the problem is ongoing, ask your doctor about collecting sperm.

Chemotherapy may reduce or stop sperm production and affect the ability of sperm to move. This can sometimes cause temporary or permanent infertility.

If you have radiation therapy in the pelvic or groin area, you may have temporary or permanent fertility problems after treatment. If your testicles are outside the treatment area, they can usually be protected. Radiation therapy to the brain may damage the pituitary gland, which affects both the production of sperm and sex drive.



Tips for managing fertility and treatment

- If you think you may want to have children in the future, discuss ways to preserve or protect your fertility with a fertility specialist before cancer treatment begins.
- Share your feelings about any fertility issues with your partner, who may also be worried or grieving.
- Ask your doctor what precautions to use during treatment. You may need to use barrier contraception, such as condoms or female condoms, to reduce any potential risk of the treatments harming a developing baby or being toxic to your partner.
- Tell your cancer specialist immediately if you or your partner become pregnant during treatment.
- Consider having tests to check if your fertility has been affected.

Key points about specific challenges

Talk openly

- Communicating openly with your partner may help you overcome any sexual problems caused by cancer treatment.
 - If you find that the changes after cancer are getting in the way of a fulfilling sex life, talk to your GP or cancer specialist about seeing a sex therapist.
-

Emotional issues

- The loss of any body part can affect your sexual confidence. Take time to get used to the changes and explore how your sexual response has changed. Remember that you are loved for who you are, not for particular body parts.
 - Loss of interest in sex (low libido) and difficulty with sexual arousal during cancer treatment are very common because you may feel too sick, tired, weak or worried to think about sex, or the treatments may have changed your body's normal hormone balance.
-

Physical issues

- Physical changes and fatigue may make some of your usual sexual practices and positions uncomfortable or painful. Try to have an open mind about exploring new ways of giving and receiving sexual pleasure.
 - Some cancer treatments can cause temporary or permanent infertility. If you think you may want to have children in the future, talk to your doctor before treatment begins.
-

Concerns for partners

It can be difficult watching someone you love go through treatment for cancer. Try to look after yourself – give yourself some time out and share your worries or concerns with somebody neutral, such as a counsellor or your doctor.

If you have been your partner's primary carer, it can sometimes be hard to switch between the roles of carer and lover. You may find that changing the setting (e.g. dinner out or a weekend away) can help you both relax and focus on things other than cancer.

Worrying about cancer and the way it may affect your life can interfere with your desire for sex, yet your partner may be craving physical contact. On the other hand, it may seem that your partner has lost interest in sex, and you may feel guilty or uncomfortable for even bringing up the topic for fear of placing pressure or appearing unsupportive. It's important to never pressure your partner to have sex or go beyond the physical boundaries they feel comfortable with.

Some people are content in a relationship without sex, but there are ways to rekindle this part of the relationship if you are missing it. See the next 2 pages for ways to improve communication and ideas for starting a conversation about your sex life.

“My husband has more sexual needs than me, and during my treatment he didn't pressure me or make me feel bad about not initiating sex...I really appreciated it.” CATHERINE

Ways to communicate

Communicate openly – Talking and sharing will be more important than ever. It may help you avoid frustrations that can arise from misunderstandings. If you and your partner have rarely talked about sex, or you find it difficult to discuss your different needs without both becoming defensive, consider asking for help. A counsellor, sex therapist or psychologist can suggest ways to approach tough conversations. They can help you talk about your sexual concerns and how the physical needs in the relationship can be met.

Try other forms of intimacy – If your partner is not ready for sexual contact, then touching, holding, hugging and massaging can help you feel close. It shows that you love and find them physically attractive. Physical contact that doesn't lead to sex can still be comforting and often helps to take the pressure off both of you. Ask how they like to be touched. Stroking their scars may show your partner that you have accepted the changes to their body. If you are finding the changes hard, try talking sensitively to your partner or to a counsellor.

Acknowledge your feelings – You may have had to face the possibility that your partner could die. As they have recovered, you may expect to feel relieved but instead feel emotionally low and drained of energy. Acknowledge that you both have been through a difficult and confronting experience, and allow yourselves time to adjust.

Look after yourself – Relationships are often challenged through a cancer diagnosis. Take time to look after yourself. Although you don't have cancer, you have also been affected. Try looking at the changes to the relationship and how you can readjust life around them.

- ▶ See our *Caring for Someone with Cancer* booklet and listen to our “Cancer Affects the Carer Too” podcast episode.

Safety concerns for partners

Be assured that it is not possible for your partner to give you cancer through intimate activities such as kissing or sex. Ask your health care team for more information.

Sexual activity will not cause the cancer to spread, nor will it make the cancer come back.

Chemotherapy drugs may stay in your partner's body fluids for several days. Their doctor may advise using condoms or other barrier methods if you are having any type of sex after treatment, so as to protect you from any potential risk. The treatment team can give you more details about how long you may need to use protection.

Some chemotherapy drugs may be passed into body fluids such as saliva. Ask the treatment team whether you need to avoid open-mouth kissing and for how long.

It will usually be safe to have sex after radiation therapy. If your partner is having external radiation therapy, they will not be radioactive by the time they return home. If your partner is having internal radiation therapy, you may need to take some precautions, such as avoiding sexual contact or using condoms or other barrier methods for a certain period of time. Your partner's treatment team will be able to give you more information.

If your partner is receiving immunotherapy for bladder cancer (Bacillus Calmette-Guérin, or BCG), ask their treatment team what precautions you need to take. You will usually need to use condoms, or other barrier methods, for a week after each treatment.

“I took hold of my partner’s hand...Her response was, ‘Do you realise this is the first time that you’ve touched me in 3 weeks?’, and I’m a fairly tactile person.” IAN



Seeking support

A cancer diagnosis can affect every aspect of your life. You will probably experience a range of emotions – fear, sadness, anxiety, anger and frustration are all common reactions. Cancer also often creates practical and financial issues.

There are many sources of support and information to help you, your family and carers navigate all stages of the cancer experience, including:

- information about cancer and its treatment
- access to benefits and programs to ease the financial impact of cancer treatment
- home care services, such as Meals on Wheels, visiting nurses and home help
- aids and appliances
- support groups and programs
- counselling services
- exercise programs.

The availability of services may vary depending on where you live, and some services will be free but others might have a cost.

To find good sources of support and information, you can talk to the social worker or cancer nurse at your hospital or treatment centre, or get in touch with Cancer Council 13 11 20.

“My family members don’t really understand what it’s like to have cancer thrown at you, but in my support group, I don’t have to explain.” SAM

Support from Cancer Council

Cancer Council offers a range of services to support people affected by cancer, their families and friends. Services may vary by location.

Cancer Council 13 11 20



Our experienced health professionals will answer any questions you have about your situation and link you to local services (see inside back cover).

Information resources



Cancer Council produces booklets and fact sheets on more than 25 types of cancer, as well as treatments, emotional and practical issues, and recovery. Call 13 11 20 or visit your local Cancer Council website.

Legal and financial support



If you need advice on legal or financial issues, we can refer you to qualified professionals. These services are free for people who can't afford to pay. Financial assistance may also be available. Call Cancer Council 13 11 20 to ask if you are eligible.

Practical help



Cancer Council can help you find services or offer guidance to manage the practical impacts of cancer. This may include helping you access accommodation and transport services.

Peer support services



You might find it helpful to share your thoughts and experiences with other people affected by cancer. Cancer Council can link you with individuals or support groups by phone, in person, or online. Call 13 11 20 or visit cancerCouncil.com.au/OC.

Useful websites

You can find many useful resources online, but not all websites are reliable. These websites are good sources of support and information.

Australian

| | |
|--|--|
| Cancer Council Australia | cancer.org.au |
| Cancer Council Online Community | cancercouncil.com.au/OC |
| Cancer Council podcasts | cancercouncil.com.au/podcasts |
| Australasian Menopause Society | menopause.org.au |
| Australian Council of Stoma Associations | australianstoma.com.au |
| Australian Physiotherapy Association | choose.physio |
| Australian Psychological Society | psychology.org.au |
| Cancer Australia | canceraustralia.gov.au |
| Carer Gateway | carergateway.gov.au |
| Carers Australia | carersaustralia.com.au |
| Continence Foundation of Australia | continence.org.au |
| Healthy Male | healthymale.org.au |
| Jean Hailes for Women's Health | jeanhailes.org.au |
| Pelvic Pain Foundation of Australia | pelvicpain.org.au |
| Prostate Cancer Foundation of Australia | pcfa.org.au |
| QLife | qlife.org.au |
| Relationships Australia | relationships.org.au |
| Society of Australian Sexologists | societyaustraliansexologists.org.au |

International

| | |
|-------------------------------|--|
| American Cancer Society | cancer.org |
| Macmillan Cancer Support (UK) | macmillan.org.uk |

Question checklist

Below is a list of suggested questions to get the conversation started with your health professional.

Sexuality during treatment

- Will this treatment affect my sex life, libido or sexuality?
 - What are the risks of treatment? Is there any chance this could permanently affect my sex life?
 - What can be done so I can keep enjoying sex and preserve sexual function?
 - How will this treatment affect my hormones?
 - Will this treatment affect my fertility? What can I do about it?
 - What changes are likely to be temporary? How long will they last? Are any changes permanent?
 - What treatment options are available to help with sexual issues after cancer?
 - When is it safe to have sex again?
 - When can I expect to feel like, or enjoy, having sex or being intimate again? How soon can I masturbate?
 - I want to have sex but I have no sexual thoughts and find it hard to feel aroused. What can I do?
-

Side effects and safety concerns

- What sort of problems might we experience during intercourse or penetration?
 - It hurts when we have sex. What can we do about this?
 - Should we take any precautions when having sex?
 - What kind of contraception should we use and for how long? Is it safe to get pregnant?
 - I am having trouble feeling confident about my body and reaching orgasm. Will it always be like this?
 - I'm afraid I can't satisfy my partner any more. What can I do?
 - Sex doesn't feel the same as it used to. What can I do?
 - Is there anything I should be careful about when I have sex?
 - Will the cancer come back if I have sex?
-

Side effects and safety concerns – continued

- I just don't have any feelings of sexual desire any more, is there anything that could help?
- Are there complementary therapies I could try? Or over-the-counter products I should avoid?
- Can you refer me to a sex therapist?
- Will I still experience the same sexual sensations after having this treatment?
- Will menopause hormone therapy be necessary? Or can it be beneficial?
- I have vaginal dryness. What do you recommend?
- Is it safe to use an oestrogen cream?
- I have pain when we try to have intercourse. What's going on and how can I get help?
- How can I stretch my vagina? Is it safe and who can help me learn about vaginal dilators?
- How can I manage the symptoms of menopause?
- Why can't I get an erection? Will this be temporary?
- What are the options if I can't get an erection?
- Why don't I ejaculate anymore?
- What can I do if I have pain during sex or when I get an erection?
- What are the fertility preservation options available to me?

LGBTQI+ specific questions

- Is this clinic LGBTQI+ friendly?
- Can you recommend a sex therapist who is LGBTQI+ friendly?
- Will you include my partner in discussions about my sexual concerns and treatment options?
- How will cancer treatment interact with gender affirmation hormones?
- Do you know of any LGBTQI+ support groups?

Glossary

adrenal glands

Small glands on top of each kidney that produce adrenaline and other hormones.

androgen

A type of hormone that produces male physical characteristics such as facial hair or a deep voice. The main androgen, testosterone, is produced by the testicles.

androgen deprivation therapy (ADT)

See hormone therapy.

Bartholin (greater vestibular) glands

Small glands on either side of the vagina that secrete mucus for lubrication.

body image

How you feel about yourself and what you think when you look at yourself.

brachytherapy

A type of internal radiation therapy in which sealed radioactive sources are placed inside the body, close to or inside the cancer. May be temporary or permanent.

breast-conserving surgery

Surgery that removes a lump without removing the entire breast. Also called a lumpectomy or wide local excision.

breast reconstruction

Surgery to rebuild the breast shape after the removal of all or part of the breast.

catheter

A hollow, flexible tube through which fluids can be passed into the body or drained from it.

cervix (neck of the uterus)

The lower part of the uterus connecting the uterus to the vagina.

chemotherapy

A cancer treatment that uses drugs to kill cancer cells or slow their growth.

climax

The peak of sexual response. Also known as orgasm.

clitoris

The main sexual pleasure organ for females. It is made up of erectile tissue with rich sensory nerve endings and becomes erect when stimulated.

cytotoxic drug

A substance (e.g. chemotherapy) toxic to cells, so it can kill or slow the growth of cancer.

dental dam

A silky, thin sheet of latex used when having protected oral sex.

depression

Very low mood and loss of interest in life, lasting for more than 2 weeks.

dry orgasm

Sexual climax without the release of semen from the penis (ejaculation).

ejaculation

When semen passes through the urethra and out of the penis during an orgasm.

erectile dysfunction

Inability to get and keep an erection firm enough for penetration. Also called impotence.

erection

An enlarged, rigid penis (sexual excitement).

erogenous zones

Areas of the body that respond to sexual stimulation or touch.

fallopian tubes

The two thin tubes that extend from the ovaries to the uterus. The tubes carry sperm to the egg, and a fertilised egg from the ovary to the uterus.

fatigue

Extreme feeling of tiredness and lack of energy.

fertility

The ability to conceive a child.

gender/gender identity

The sense of whether you are a man, woman, non-binary, agender, genderqueer, genderfluid, or a combination of one or more of these definitions. Gender can be binary (either a man or a woman), or non-binary (including people who have no binary gender and people who have some binary gender/s).

genitals

The sex organs. Often used to mean the external sexual organs.

gynaecological cancers

Cancers of the female reproductive system. They include cervical, ovarian, uterine, vaginal and vulvar cancers.

hormone replacement therapy (HRT)

See menopause hormone therapy (MHT).

hormones

Chemicals in the body that send information between cells. Some hormones control growth, others control reproduction.

hormone therapy

A treatment that blocks the body's natural hormones, which sometimes help cancer cells grow. Also called endocrine therapy (or androgen deprivation therapy in males).

hysterectomy

The surgical removal of the uterus.

immunotherapy

Treatment that uses the body's own immune system to fight cancer.

impotence

See erectile dysfunction.

incontinence

The accidental or involuntary loss of urine (wee or pee) or faeces (poo).

infertility

The inability to conceive a child or difficulty after trying for a year, or 6 months if over 35.

intersex

A term used to describe a person born with anatomical, reproductive or chromosomal characteristics that are not typically female or male.

intimacy

Being physically and emotionally close to someone.

labia majora

The outer lips of the vulva.

labia minora

The inner lips of the vulva.

LGBTQI+

A commonly used acronym for people of diverse genders and sexualities. It refers to those who identify as lesbian, gay, bisexual, transgender, queer or questioning, intersex or other sexualities such as asexual or pansexual.

libido

Sex drive/sexual desire.

lumpectomy

See breast-conserving surgery.

lymphadenectomy

Removal of the lymph glands from a part of the body. Also called a lymph node dissection.

lymph nodes

Small, bean-shaped structures that collect and destroy bacteria and viruses. Also called lymph glands.

lymphoedema

Swelling caused by a build-up of lymph fluid. This happens when lymph vessels or nodes can't drain properly because they have been removed or damaged.

mastectomy

Surgery to remove the whole breast.

masturbation

Stimulation of your own or a partner's genitals without sexual intercourse for pleasure or orgasm.

menopause

When someone stops menstruating (having periods). This can happen naturally; because of chemotherapy, radiation therapy or hormone therapy; or because the ovaries have been removed.

menopause hormone therapy (MHT)

Drug therapy that supplies the body with hormones that it is no longer able to produce naturally. Previously known as hormone replacement therapy (HRT).

mons pubis

The area of fatty tissue above the labia. It is covered with pubic hair.

oestrogen

A sex hormone made mainly by the ovaries. After menopause, the hormone is produced in the fat cells.

oophorectomy

Surgery to remove an ovary. If both ovaries are removed, it is called a bilateral oophorectomy.

orchidectomy

Surgery to remove one or both testicles. Also called orchietomy.

orgasm

Sexual climax.

osteoporosis

Thinning and weakening of the bones that can lead to bone pain and fractures. Osteopenia is milder bone thinning.

ovary

A female reproductive organ that contains eggs (ova). It produces the hormones oestrogen and progesterone.

ovulation

The release of an egg (ovum) during the menstrual cycle.

pelvic floor exercises

Exercises to strengthen the muscles controlling the bladder and rectum.

pelvis

The lower part of the trunk of the body: roughly, the area that extends from hip to hip and waist to groin.

penectomy

Surgery to remove part or all of the penis.

penile prosthesis

An implant that is surgically inserted into the penis to mechanically create an erection.

perineum

The area of skin between the vulva and the anus, or between the scrotum and the anus.

premature/early menopause

Menopause that occurs before 40.

premature ejaculation (PE)

The inability to delay ejaculation.

premature ovarian insufficiency (POI)

The premature loss of ovarian function before the age of 40.

progesterone

A sex hormone made mostly by the ovaries. It prepares the uterus lining (endometrium) for pregnancy.

prostate

A gland that is part of the male reproductive system. It produces fluid that makes up part of semen.

prostatectomy

Surgery to remove all or part of the prostate gland.

protheses

Artificial replacements for a removed or damaged body part.

radiation therapy

The use of targeted radiation to kill or damage cancer cells so they cannot grow, multiply or spread. Also called radiotherapy.

retrograde ejaculation

A condition where the sperm travels backwards into the bladder, instead of forwards out of the penis.

scrotum

The external pouch of skin behind the penis that contains the testicles.

semen

The fluid ejaculated from the penis during sexual climax. It contains sperm from the testicles and fluids from the prostate and seminal vesicles.

seminal vesicles

Two small glands that lie near the prostate and produce fluid that forms part of semen.

sex

1. Penetrative intercourse and other activities such as oral sex and self-stimulation/masturbation.
2. The anatomical gender that you identify with (male, female, intersex).

sexual arousal

The ability for the body to respond and get turned on.

sexual desire

Wanting to have sex. Also called libido.

sexuality

How people express themselves as sexual beings.

sexual orientation

Describes the people that you are sexually attracted to. For example, heterosexual is an attraction to the opposite sex, homosexual is an attraction to the same sex, and an attraction to both sexes is bisexual.

sexual response cycle

The phases of physical response during sexual arousal and intercourse. This may include arousal (excitement), desire, plateau, orgasm and resolution.

side effect

Unintended effect of a drug or treatment.

sperm

The male sex cell.

stoma

A surgically created opening to allow urine or faeces to leave the body. Also called ostomy.

targeted therapy

Drugs that target specific features of cancer cells to stop the cancer growing and spreading.

testicles

Two oval-shaped glands that produce sperm and the male sex hormone testosterone. They are found in the scrotum. Also called testes.

testosterone

The main sex hormone in males. It is made by the testicles and promotes the development of male sex characteristics.

transgender

A term for a person whose gender identity does not match their sex assigned at birth.

urethra

The tube that carries urine from the bladder to the outside of the body. In males, the urethra also carries semen.

uterus

A hollow organ in which a fertilised egg (ovum) grows and a fetus is nourished until birth. Also called the womb.

vagina

A muscular canal that extends from the entrance of the uterus to the vulva.

vaginal stenosis

Narrowing of the vagina.

vaginectomy

An operation that removes some or all of the vagina.

vaginismus

A spasm in the vaginal or pelvic muscles that may prevent sexual intercourse.

vas deferens

A pair of tubes that carry sperm from the testicles to the prostate.

vulva

The external sexual organs (genitals) of a female. It includes the mons pubis, labia majora and minora, and clitoris.

vulvectomy

Removal of some or all of the vulva.

womb

See uterus.

Can't find a word here?

For more cancer-related words, visit:

- cancerCouncil.com.au/words
- cancervic.org.au/glossary

References

1. We have used quotes from cancer survivors who took part in the Western Sydney University research project “Multiple perspectives on sexuality and intimacy post-cancer, leading to the development and evaluation of supportive interventions”, which has been funded by the Australian Research Council, in partnership with Cancer Council NSW and National Breast Cancer Foundation.
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How you can help

At Cancer Council, we're dedicated to improving cancer control. As well as funding millions of dollars in cancer research every year, we advocate for the highest quality care for cancer patients and their families. We create cancer-smart communities by educating people about cancer, its prevention and early detection. We offer a range of practical and support services for people and families affected by cancer. All these programs would not be possible without community support, great and small.

Join a Cancer Council event: Join one of our community fundraising events such as Daffodil Day, Australia's Biggest Morning Tea, Relay For Life, Girls' Night In and other Pink events, or hold your own fundraiser or become a volunteer.

Make a donation: Any gift, large or small, makes a meaningful contribution to our work in supporting people with cancer and their families now and in the future.

Buy Cancer Council sun protection products: Every purchase helps you prevent cancer and contribute financially to our goals.

Help us speak out for a cancer-smart community: We are a leading advocate for cancer prevention and improved patient services. You can help us speak out on important cancer issues and help us improve cancer awareness by living and promoting a cancer-smart lifestyle.

Join a research study: Cancer Council funds and carries out research investigating the causes, management, outcomes and impacts of different cancers. You may be able to join a study.

To find out more about how you, your family and friends can help, please call your local Cancer Council.



Cancer Council

13 11 20

Being diagnosed with cancer can be overwhelming. At Cancer Council, we understand it isn't just about the treatment or prognosis. Having cancer affects the way you live, work and think. It can also affect our most important relationships.

When disruption and change happen in our lives, talking to someone who understands can make a big difference. Cancer Council has been providing information and support to people affected by cancer for over 50 years.

Calling 13 11 20 gives you access to trustworthy information that is relevant to you. Our experienced health professionals are available to answer your questions and link you to services in your area, such as transport, accommodation and home help. We can also help with other matters, such as legal and financial advice.

If you are finding it hard to navigate through the health care system, or just need someone to listen to your immediate concerns, call 13 11 20 and find out how we can support you, your family and friends.



If you need information in a language other than English, an interpreting service is available. Call 131 450.



If you are deaf, or have a hearing or speech impairment, you can contact us through the National Relay Service. communications.gov.au/accesshub/nrs

*Cancer Council services and programs vary in each area.
13 11 20 is charged at a local call rate throughout Australia (except from mobiles).*

For information & support
on cancer-related issues,
call **Cancer Council 13 11 20**

Visit your local Cancer Council website

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actcancer.org

Cancer Council NSW
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Cancer Council NT
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