



Sexuality, Intimacy and Cancer

A guide for people with cancer
and their partners

Practical
and support
information

For information & support, call

13 11 20



Sexuality, Intimacy and Cancer

A guide for people with cancer and their partners

First published June 2009. This edition May 2019.

© Cancer Council Australia 2019. ISBN 978 1 925651 50 8

Sexuality, Intimacy and Cancer is reviewed approximately every three years. Check the publication date above to ensure this copy is up to date.

Editor: Jenny Mothoneos. Designer: Eleonora Pelosi. Printer: SOS Print + Media Group.

Acknowledgements

This edition has been developed by Cancer Council NSW on behalf of all other state and territory Cancer Councils as part of a National Cancer Information Subcommittee initiative.

We thank the reviewers of this booklet: Helena Green, Clinical Sexologist and Counsellor, inSync for Life, WA; Anita Brown-Major, Occupational Therapist, Thrive Rehab, VIC; Karina Campbell, Consumer; Nicole Kinnane, Nurse Consultant, Gynae-oncology Services, Peter MacCallum Cancer Centre, VIC; Jessica Medd, Senior Clinical Psychologist, Headway Health and Concord Hospital, NSW; Chris Rivett, 13 11 20 Consultant, Cancer Council SA; Kath Schubach, Urology Nurse Practitioner, President – Australia and New Zealand Urological Nurses Society (ANZUNS), VIC; Prof Jane Ussher, Chair, Women's Health Psychology, Translational Health Research Institute (THRI), School of Medicine, Western Sydney University, NSW; Maria Voukelatos, Consumer. We would like to thank the health professionals, consumers and editorial teams who have worked on previous editions of this title.

This booklet is funded through the generosity of the people of Australia.

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 Australia

Level 14, 477 Pitt Street, Sydney NSW 2000

Telephone 02 8063 4100 **Facsimile** 02 8063 4101

Email info@cancer.org.au **Website** cancer.org.au

ABN 91 130 793 725

About this booklet

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

Sexuality and intimacy are an important part of our wellbeing. Sexuality is part of how we experience physical and emotional closeness, and how we develop and maintain our intimate relationships. It is closely linked to how we relate to ourselves and others.

We hope this booklet helps you find practical ways to adapt to any physical and emotional changes you experience, and discover new ways to enjoy intimacy. The information is relevant to all individuals, regardless of your sexual orientation and whether you are single or in a relationship. In this booklet, the term “partner” means husband, wife, de facto, same-sex partner, boyfriend or girlfriend.

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.¹⁻⁵

If you or your family have any questions, 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).



**Cancer
Council**
13 11 20

Contents

What are sexuality and intimacy?	4
Sexuality after a cancer diagnosis	5
How does cancer affect sexuality?	5
Do people really think about sex when they have cancer?	6
Will my doctor want to talk about sexuality?	6
Who else can I talk to?	7
How soon can I have sex?	8
Can sex make the cancer worse?	8
Will I ever enjoy sex again?	8
Are there dangers for my partner?	9
How can we feel like sexual partners again?	9
What if I don't have a partner?	9
The sexual response	10
Stages of the sexual response cycle.....	10
Erogenous zones.....	10
The role of hormones	11
The female sexual and reproductive anatomy	12
The male sexual anatomy.....	14
Treatment side effects and sexuality.....	16
Emotions and sexuality	16
Surgery	19
Radiation therapy	23
Chemotherapy.....	25
Hormone therapy	27
Immunotherapy and targeted therapy.....	28
Palliative treatment.....	29

Resuming sexual activity after treatment 31

Adapting to changes 32
Communicating with your partner 35
Communicating with a new partner 36

Overcoming specific challenges 38

Fatigue 38
Sadness and depression 39
Anxiety 40
Loss of sexual pleasure 41
Loss of desire 42
Erection problems 44
Changes in ejaculation 46
Difficulty reaching orgasm 47
Changes to the vagina 48
Pain 52
Incontinence 54
Changes in appearance 56
Removal of a body part 58
Adapting to life with a stoma 60
Adapting to life after a brain tumour 61
Early menopause 62
Fertility issues 64

Concerns for partners 67

Ways to communicate 67

Seeking support 70

Question checklist 73

Glossary 75

How you can help 80



What are sexuality and intimacy?

Sexuality 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 many ways, such as by the clothes you wear, the way you move, the way you have sex, and who you have sex with.

Sexuality is different from sexual orientation, which is the attraction you feel towards another person, for example you might be heterosexual (“straight”), homosexual (“gay or lesbian”), bisexual or asexual. You might identify as LGBTI (lesbian, gay, bisexual, transgender, intersex).

The role that sexuality plays in your life is influenced by your age, environment, health, relationships, culture and beliefs, opportunities and interests, and how you feel about yourself (self-esteem).

Sex is often considered intercourse with penetration, but it can also include touching, kissing, self-stimulation and oral sex. Sex is a way to experience intimacy, but intimacy is not necessarily about sex. Being intimate means being physically and emotionally close to someone else. Intimacy is about:

- loving and being loved
- demonstrating mutual care and concern
- showing you value another person and feeling valued in return.

Intimacy is also expressed in different ways: by talking and listening on a personal level; by sharing a special place or a meaningful experience; and through physical affection. Most people need some physical connection to others. Even for people who are not sexually active, touch is still important.



Sexuality after a cancer diagnosis

Q: How does cancer affect sexuality?

A: Cancer and its treatment can change your body and how you feel about yourself, which can affect your sexuality. The most obvious impacts are physical. Treatment for some types of cancer can directly affect your physical ability to have sex or to enjoy it. More generally, many cancer treatments can affect your ability or desire to be intimate with others.

A cancer diagnosis can also influence your body image, emotions and relationships, all of which can change how you feel about sex. Cancer and its treatment can often make existing stresses more intense. If there have been issues in your sexual relationship (or in your relationship more generally) before the diagnosis, these may get worse, and it becomes all the more important to deal with them.

Most people who have had cancer treatment say they have experienced issues with sexuality and intimacy.² Some find that any change in their sexuality is temporary. Others have to adapt to long-term changes, and may find this to be the most difficult aspect of life after cancer. It is possible, however, for the changes to strengthen a relationship, improve how you communicate, and lead to new ways to express sexuality and intimacy.

“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: Research shows that people who have cancer think about their sexuality, even when cancer is advanced. During the initial shock of diagnosis, sex might be the furthest thing from your mind. Over time, however, you may have questions about the likely impact of treatments and when you can resume sexual activity. Maintaining or regaining a fulfilling sexual and intimate life after a cancer diagnosis can allow people to feel normal.

Q: Will my doctor want to talk about sexuality?

A: Sex is a private matter and many people, including health professionals, may feel uncomfortable discussing sexual concerns. You might assume that the doctor will bring up the subject, but this doesn't always happen. Or you might think there is no point because you don't realise that there are treatment options available. Sometimes your doctor may not be able to offer you the time and privacy needed for a sensitive discussion. These reasons may mean that the topic is overlooked.

There are ways to improve sex and sexuality if you share your concerns with your health care team (see page opposite). Some health professionals may not know the answer but can direct you to other health professionals who can help. You can also ask for a referral to someone else if you are same-sex attracted or transgender and feel that your health professional is uncomfortable talking about your sexual practices.

Q: Who else can I talk to?

A: You can talk about your concerns with your GP or someone on your health care team you feel comfortable with.

Health professionals who can help

nurse	administers drugs and provides care, information and support throughout treatment
cancer care coordinator	coordinates your care, 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 your pelvic floor muscles and improve incontinence and pelvic health
occupational therapist	assists in adapting your working and living 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	help you manage your emotional response to diagnosis and treatment; provide support and advice about sexuality and intimacy
sexual health physician*, sex therapist	can help you and your partner with sexuality issues before and after treatment
social worker	links you to support services and helps you with emotional, practical and financial issues

**Specialist doctor*

Q: How soon can I have sex?

A: This will vary depending on the treatment you have had and the speed of your recovery – both physically and emotionally. Your doctor will tell you how long you need to wait before resuming particular sexual practices, such as penetrative intercourse. This waiting period is for medical reasons, such as preventing injury or infection after surgery. It can be considered the minimum period. It's normal to feel hesitant or nervous about resuming sexual activity after cancer treatment.

Q: Can sex make the cancer worse?

A: Sexual activity will not make the cancer worse or make it come back. In fact, the emotional benefits of physical affection may help you cope with treatment and recovery.

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. Like any new skill this will take time and practice. Some people say that because they try new things, their sex lives actually end up being much better after cancer.



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

Q: Are there dangers for my partner?

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, for a short time. See *Safety concerns for partners*, page 69.

Q: How can we feel like sexual partners again?

A: Relationships often change during cancer treatment. 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.

Q: What if I don’t have a partner?

A: If you don’t have a partner, you may not think about raising sexual issues with your treatment team. However, your sexuality is as important as anyone else’s and your treatment team should openly discuss any concerns you have.

You may be worried about finding a new partner after cancer treatment and how you will tell them about the effects of the cancer. See page 34 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 for a future relationship.



The sexual response

Your interest in having sex – also known as sexual desire or libido – 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 also creates 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 the 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. Both males and females experience these phases, although the timing can be different, and you may not go through all the stages – you can become aroused and achieve orgasm as a result of a partner's sexual interest but not have felt sexual desire beforehand.

Erogenous zones

Areas of the body that 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, 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.

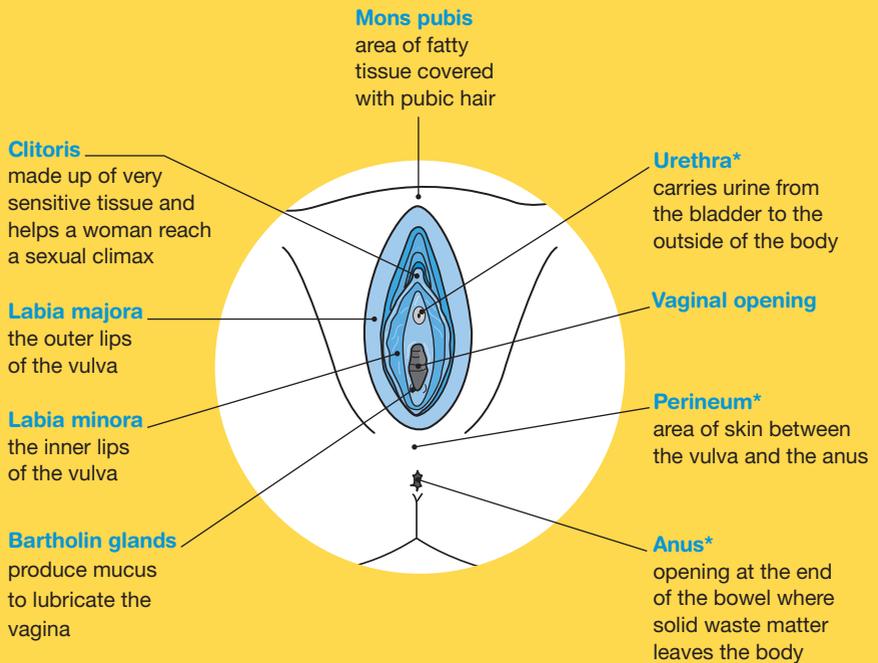
Male sex hormones (androgens) – The major male sex hormone is testosterone, which is produced mostly in the testicles and also in the adrenal glands. Testosterone causes the development of the reproductive organs and other sexual characteristics, such as a deep voice and body and facial hair. Cancer treatments that lower testosterone hormone levels, such as testosterone-blocking drugs for prostate cancer, can affect the ability to get or keep an erection and reduce desire for sex.

Female sex hormones – The major female sex hormones are oestrogen and progesterone. Oestrogen keeps the vagina moist and supple, while progesterone controls reproduction. Both these hormones are produced mostly in the ovaries until menopause, when the ovaries cease releasing eggs and periods stop. Small amounts of oestrogen and progesterone are made in the adrenal glands before and after menopause. Some cancer treatments can affect a female's hormone levels in the short and long term, causing early menopause or menopause-like symptoms.

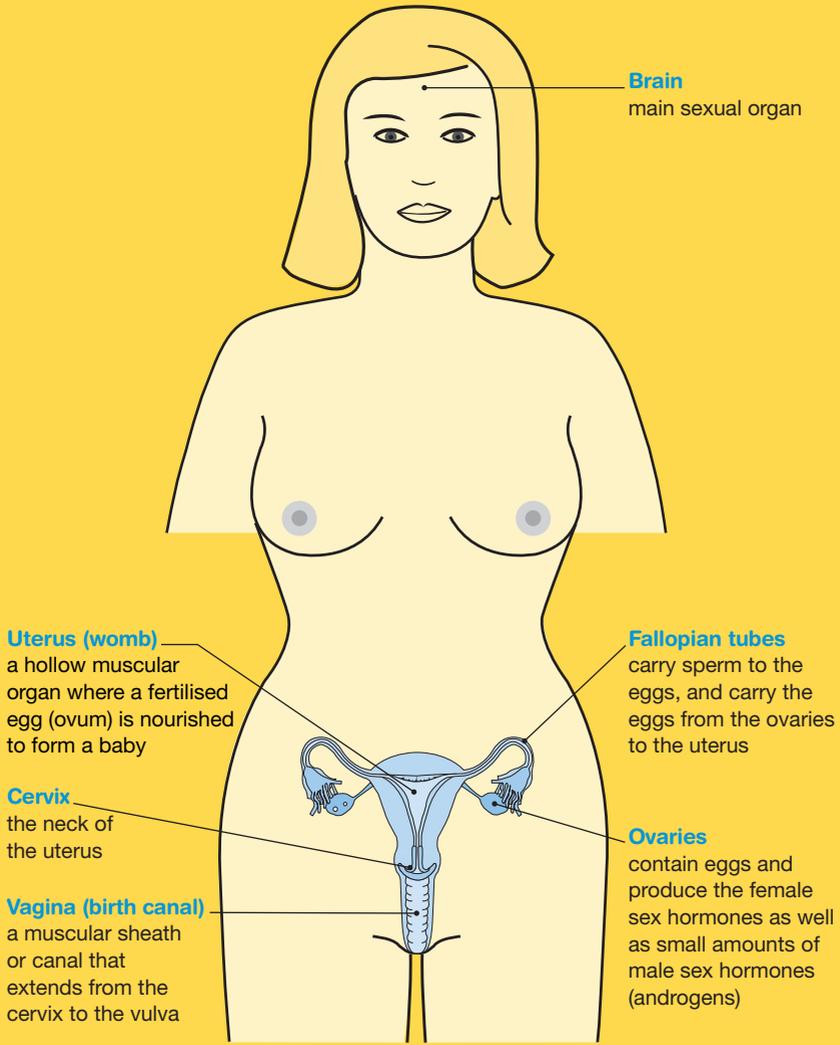
In females, the ovaries and adrenal glands also make small amounts of the male sex hormones (androgens). Androgen levels may be linked with a female's general sexual wellbeing. They decrease during and after chemotherapy and can drop suddenly if the ovaries are removed.

The female sexual and reproductive anatomy

A female's sexual and reproductive organs are located inside and outside the body. The external sex organs (genitals), known as the vulva, include the mons pubis, clitoris, labia majora, labia minora, and Bartholin glands. The reproductive organs include the fallopian tubes, ovaries, uterus, cervix and vagina. You may or may not have some of these organs.

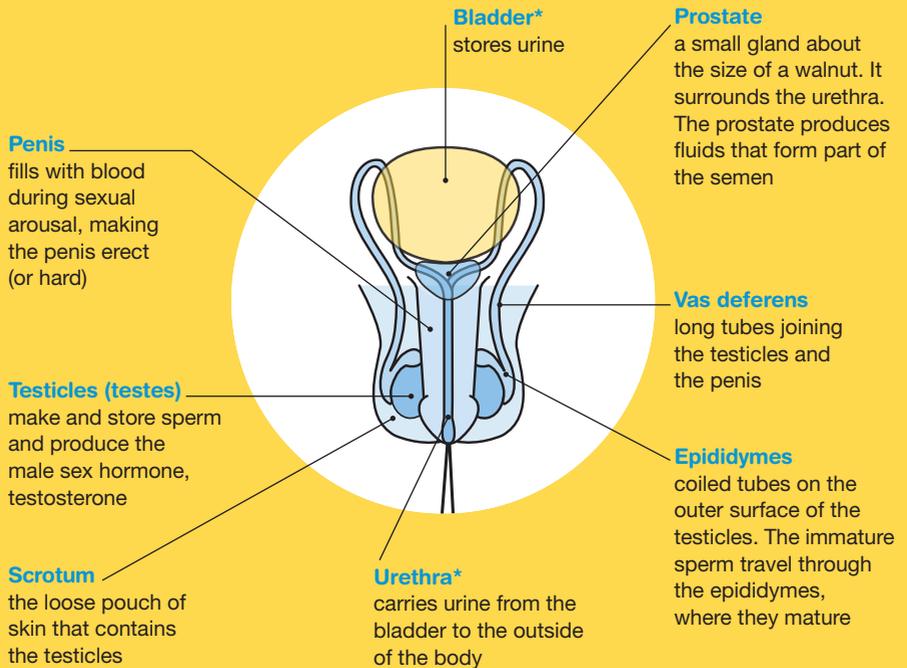


**not part of the external sexual organs or the reproductive system*

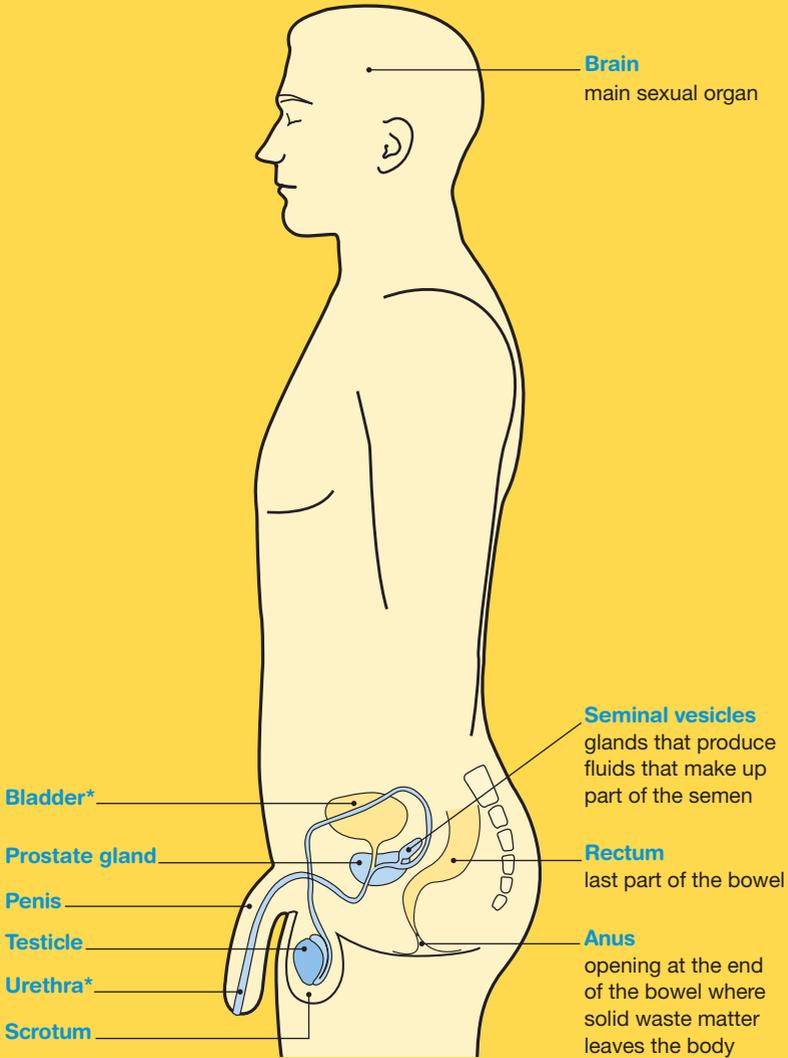


The male sexual anatomy

The male body has sexual organs both inside and outside 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 and sexuality

When you are first diagnosed with cancer, it's natural to focus on getting well. As treatment progresses, you may notice the effect on your self-esteem, body image, relationships and sex life. It usually takes time to adjust to these changes.

Emotions and sexuality

It is normal to experience a range of emotions during and after cancer treatment. Some of the emotions you may feel include:

Anger – You may feel angry about having cancer and about the ways it has affected your life, including your sexuality or your ability to have children (fertility).

Anxiety – The thought of being intimate or having sexual intercourse again after treatment may make you feel anxious. You may be unsure how you'll perform, dread being touched, or fear that penetrative intercourse will be painful. If you're single, you may feel anxious about starting a new relationship. Anxiety may affect your self-esteem and your interest in having sex.

Fear – You may worry that others will avoid or reject you when they see how your body has changed. Or you may be afraid that you're not satisfying your partner sexually, or that your partner no longer finds you sexually attractive. You may not be able to imagine yourself in a sexual situation again.

Guilt – Many people think they should just be grateful to have the cancer treated and feel guilty for thinking about their sexual needs.

Self-consciousness – If the way your body looks has changed after cancer treatment, you may feel self-conscious about being seen naked. Often people find that their partner (or a potential partner) isn't as concerned about these changes as they are.

Shame – You may feel ashamed by changes to how you look, your sexuality, or the way your body functions.

Depression – Feeling sad after a cancer diagnosis is common. If you have continued feelings of sadness, irritability or anxiety, trouble sleeping, less interest in activities you previously enjoyed, poor appetite and a reduced interest in sex (low libido), you may be experiencing depression.

Grief – You may grieve for the loss of your former body and its functioning, and your sex life if the changes are significant.

These emotions can affect your self-esteem, sexuality and attitude towards intimacy. It can help to talk about how you're feeling with someone you trust, such as your partner or a health professional, or with another person who has had cancer (see pages 70–71).

➤ See our *Emotions and Cancer* booklet.

👤👤 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

How cancer treatment affects sexuality

The most common cancer treatments are surgery, radiation therapy, chemotherapy and hormone therapy. Other treatments include immunotherapy and targeted therapy. These treatments, as well as the cancer itself, can have temporary or permanent effects on your sexuality. Some sexual problems are common, but may not be an issue for everyone. For ways to manage problems, see pages 38–66.

general	<ul style="list-style-type: none">• tiredness and fatigue• depression and anxiety• difficulty feeling pleasure during sex• loss of desire/interest in sex• painful intercourse• changed body image, e.g. due to scarring, removal of a body part, hair loss from any part of the body, skin rashes, changes in weight• loss of a body part, such as an erogenous zone or reproductive organ• incontinence• pelvic pain• fertility problems (temporary or permanent)• strain on, or changes to, your relationship(s)
females	<ul style="list-style-type: none">• vaginal dryness• reduced vaginal size• loss of sensation• pelvic pain• trouble reaching orgasm• menopausal symptoms
males	<ul style="list-style-type: none">• erection problems• ejaculation difficulties

Surgery

Surgery aims to remove cancer from the body. Many different types of surgery are used to treat cancer in different areas of the body, including:

Abdominoperineal resection – This removes the anus, rectum and part of the colon. It may be used for anal or bowel cancer. The anus is a key erogenous zone for many people. For men who have sex with men, some sexual acts may no longer be possible, but you can find new ways to express intimacy (see pages 58–59).

Breast-conserving surgery or mastectomy – This removes part of the breast (breast-conserving surgery or lumpectomy) or the whole breast (mastectomy). Breast and nipple sensation usually remain the same after breast-conserving surgery, but can change after mastectomy. This can affect sexual arousal if you previously enjoyed being touched or kissed on the breast and nipple. The loss of a breast may make you feel self-conscious and like you've lost a part of your identity. A breast reconstruction may help improve self-esteem (see pages 58–59).

If lymph nodes are removed during surgery, this may cause the arm to swell (lymphoedema). The swelling may make you feel self-conscious.

► See our *Understanding Lymphoedema* fact sheet.

Colectomy – This removes part of the colon. Sometimes one end of the bowel is brought through an opening made in your abdomen and stitched onto the skin. The opening – called a stoma – allows faeces to be collected in a bag (see page 60). Erection problems can be an issue for some men after a colectomy.

Craniotomy – Brain and spinal cord tumours may be treated with different types of operations. Depending on the part of the brain removed, surgery may cause changes in behaviour and personality, erection problems, or interest in sex. Difficulty speaking or swallowing may also occur.

Cystectomy – This removes part or all of the bladder and nearby lymph nodes. A radical cystectomy may involve removing sex organs. In females, this includes the uterus, ovaries, fallopian tubes and part of the vagina. For females who have not yet gone through menopause, removing the ovaries will cause periods to stop and you will be unable to have children naturally (see pages 62–65). In males, this includes the prostate, seminal vesicles and part of the urethra. The nerves needed for an erection are likely to be affected.

If you have a radical cystectomy, you will need another way to collect and store urine (called a urinary diversion). Often the urine will drain into a bag attached to the outside of the abdomen, which may affect your body image.

Face – Surgery to your face and mouth can change how you feel about yourself. Surgery may affect your ability to kiss or give oral sex. It may also cause problems with controlling saliva. If you have a dry mouth, kissing and oral sex may be uncomfortable.

Hysterectomy – This removes the uterus, and sometimes the cervix, fallopian tubes and ovaries. It may be used to treat gynaecological cancers, such as cancer of the cervix, ovary, uterus (womb) and endometrium (lining of the uterus), and sometimes the vagina.

If your uterus is removed, you will be unable to become pregnant and your periods will stop (menopause, see pages 62–63).

A hysterectomy may shorten the top part of the vagina, but this doesn't change your ability to have sex. The clitoris and the lining of the vagina will remain sensitive, so you will usually still be able to feel sexual pleasure and reach orgasm. If the uterus was removed, contractions in the uterus will no longer happen during orgasm, and this can affect sexual pleasure for some.

Laryngectomy – This surgery removes part or all of the voice box (larynx). Your speech will be affected and this may affect your self-esteem and ability to express yourself during sex.

Oophorectomy – If both ovaries are removed (bilateral oophorectomy) and you haven't already been through menopause, you will no longer have your monthly periods or be able to become pregnant (see pages 62–63). Hormonal changes after oophorectomy can cause vaginal dryness (see pages 48–51). If only one ovary has been removed, the other should continue to release eggs and produce hormones. You will still have periods and may be able to become pregnant if your uterus wasn't removed.

Orchidectomy or orchiectomy – If only one testicle is removed, there should be no lasting effects on your ability to have sex or your fertility. Unless there are unrelated fertility issues, your remaining testicle will make enough testosterone and sperm for you to be able to father a child. The scrotum's appearance can be improved and maintained with an artificial testicle (prosthesis, see pages 58–59).

Having both testicles removed (bilateral orchidectomy), which is rarely required, causes permanent infertility because you will no longer produce sperm. However, you may be able to 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 44–45)
- not ejaculating semen during climax (dry orgasm, see page 46)
- semen going backwards into the bladder instead of forwards (retrograde ejaculation, see page 46)
- leaking urine during sex (see page 46)
- loss of pleasure (see page 41)
- pain during orgasm (see pages 52–53)
- penile shortening.

Vagina – A small section of the vagina may be removed to treat vaginal cancer. Enough vaginal tissue should remain so you are still able to have intercourse. Some people need a larger operation that removes the whole vagina (vaginectomy). A vaginal reconstruction may be an option, but after surgery scar tissue can form and make intercourse painful and difficult.



Most people feel shocked and upset about having cancer in one of the most intimate and private areas of their body. Cancer Australia's resource *Intimacy and sexuality for women with gynaecological cancer – starting a conversation* can help you talk with your doctors.

Vulva (vulvectomy) – Removing part or all of the vulva will change the look and feel of your genital area, and can affect your body image, self-esteem and how you enjoy sex. If the clitoris has been removed, it may still be possible to have an orgasm through stimulation of other sensitive areas of your body, such as your breasts or inner thigh. However, it will take time for you and your partner to adjust to these changes (see pages 32–33 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 part of the body 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** – may be very sensitive or painful to touch
- **appetite loss** – you may lose your appetite and lose weight
- **hair loss** – you may lose some or all hair – on your scalp, face or body – during treatment. Usually it grows back and returns to normal after radiation therapy has finished.

Radiation therapy to the pelvic area – May be used for cancer of the bladder, bowel, cervix, ovary, uterus, vulva, prostate, or rectum. The radiation oncologist will try to avoid the ovaries, especially if you have not yet been through menopause. If radiation does affect the ovaries, they'll stop producing female hormones. This can cause menopausal symptoms, and your periods may become irregular or stop. Your periods may return after treatment is over, but sometimes infertility will be permanent (see pages 64–65).

Pelvic radiation therapy can cause short-term inflammation of the vagina and vulva. Scar tissue from treatment can make the vagina shorter and narrower (vaginal stenosis). Sexual intercourse may be painful, but using vaginal dilators or vibrators after treatment ends can help (see pages 48–50). Using water-based lubricants and moisturisers is also useful. In some cases oestrogen-based creams are prescribed.

Radiation therapy may also cause bowel problems, such as diarrhoea. This is usually temporary, but it is sometimes permanent.

Radiation therapy to the breast – This can cause the skin to become red and dry and develop a sunburnt look. It usually returns to normal 4–6 weeks after treatment. Radiation therapy to the armpit may increase the chance of developing lymphoedema in the arm.

Some people develop fluid in the breast 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 looks, talk to your doctor about your options (e.g. you may be able to have an operation to reduce the size of your other breast).

“ 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 testicles – This can damage the blood vessels and nerves that help produce erections, causing temporary or permanent erectile dysfunction (see pages 44–45). It may also make the urethra inflamed, so ejaculating might be painful for some weeks.

Reduced sperm production is common after radiation therapy, and it may be temporary or permanent. If you think you might want to father a child in the future, ask about storing sperm before starting 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 tiredness, nausea, vomiting, diarrhoea, constipation, hair loss and mouth ulcers – all of which may affect your self-esteem and reduce your desire to have sex.

Chemotherapy can also affect the hormones linked to libido. If you have a partner, let them know why your libido has changed. Sex drive usually returns after treatment ends.

Having chemotherapy can lower the levels of hormones produced by the ovaries. For some females, this causes periods to become irregular, but they often return to normal after treatment. For other females, chemotherapy may bring on menopause (see pages 62–63). After menopause, a female can't conceive children with her own eggs. If this is a concern for you, speak to your doctor before treatment.

Chemotherapy for ovarian or colon cancer can be given as liquid directly into the abdominal cavity. 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.

Another common side effect in females having chemotherapy (especially if they are taking steroids or antibiotics to prevent infection) is thrush, which can cause vaginal dryness, itching or burning and a whitish discharge (see page 51 for tips).

Chemotherapy for vulvar cancer may make any skin soreness caused by radiation therapy worse.

In males, chemotherapy drugs may lower the number of sperm produced and their ability to move (motility). This can cause temporary or permanent infertility (see pages 64–65). Some chemotherapy drugs can affect the nerves needed for the penis to become erect, but this is usually temporary.

Protecting your partner during chemotherapy and radiation therapy

Whatever your preferred method of contraception, you should also use some sort of barrier during any sexual activity to reduce the potential risk to your partner from cancer treatment, and to avoid pregnancy.

Chemotherapy – Use protection after treatment as the drugs may be released into your body fluids. For intercourse, use condoms or female condoms. Partners can wear latex gloves if using their

hands for penetration. If you have anal sex, use condoms. Your doctor or nurse can give you more details about how long you need to use protection.

For oral sex, use condoms or dental dams (latex squares).

Internal radiation – Avoid sexual contact or use barrier contraception (such as condoms), during treatment.

Hormone therapy

Hormones that 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) is to lower the amount of hormones the tumour receives. This can help reduce the size and slow down the spread of the cancer. Hormone therapy can be used for a short time or long term.

Oestrogen helps some types of breast cancer to grow. Anti-oestrogen drugs (such as tamoxifen, goserelin and aromatase inhibitors) are used in hormone therapy to treat oestrogen-sensitive cancers. They can help slow or stop new breast cancers developing. Some people

have no side effects from these 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 after hormone therapy as there is a small risk of developing cancer in the lining of the uterus (endometrial cancer).

Androgen deprivation therapy (ADT) is a type of hormone therapy that slows the production of testosterone. If you have ADT to treat prostate cancer, you may feel tired, or have erection problems, reduced sex drive, weight gain, hot flushes, breast growth and tenderness, depression, and loss of bone density (osteoporosis).

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 disease. 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 desire for or ability to have sex. Your doctor will explain if you need to use protection during sex after having these therapies.

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

Palliative treatment

Palliative treatment helps to improve people's quality of life by managing the symptoms of cancer without trying to cure the disease. It is best thought of as supportive care. Many people think that palliative treatment is for people at the end of life, but it may be beneficial for people at any stage of advanced cancer. As well as slowing the spread of cancer, palliative treatment can relieve pain and help manage other symptoms. Treatment may include surgery, radiation therapy, chemotherapy, hormone therapy, targeted therapies or other medicines.

Many people say that sexuality and intimacy remain important to them even when cancer is advanced. It is 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 time together as a couple, rather than as "patient" and "carer", during palliative treatment. Ask your treatment team if it's possible to use a double bed so you can cuddle with your partner. 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.

Palliative treatment is one aspect of palliative care, in which a team of health professionals aim to meet your physical, emotional, practical, spiritual and social needs. The team also provides support to families and carers.

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



Key points about sexuality and treatment

- Main treatments**
- The main cancer treatments are surgery, radiation therapy, chemotherapy and hormone therapy (endocrine therapy).
 - It is difficult to predict how treatment will affect you. Changes can be temporary, longer-lasting or permanent.
 - It is natural to feel a range of emotions. These can include anger, anxiety, fear, guilt, self-consciousness, shame, depression and grief, which can all affect sexuality.

Sexuality and cancer treatments

- The side effects of cancer treatments can lower your libido and arousal, and can reduce your desire for sexual intimacy.
- 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 tiredness, decreased libido, weight gain, hot flushes, loss of bone density, breast tenderness, increased breast tissue, and depression. Females may experience additional menopause-like symptoms.
- Even when cancer is advanced, sexuality and intimacy may remain important. Discuss any concerns you have with your medical team.



Resuming sexual activity after treatment

While some people find sexual intimacy is the last thing on their minds during treatment, others 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 a relationship, 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 may become less comfortable temporarily or change over time. To adapt to these changes, you may need to be more open and confident, in and out of the bedroom. Try to explore different ways to feel sexual pleasure.

What if I identify as LGBTI?

It is important to feel that your sexuality is respected when discussing how treatment will affect you. Acceptance of your sexuality is an important part of receiving support. Your clinical team should openly discuss your sexual needs and support you throughout treatment.

Try to find a doctor, nurse or counsellor who is comfortable discussing your sexual issues and relationships. You could

also contact QLife, a national counselling and referral service for people who are lesbian, gay, bisexual, trans and/or intersex (LGBTI). Visit qlife.org.au or call **1800 184 527**.

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

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're ready to have sex, what level of intensity you prefer, if they should do anything differently and how they can help you to feel pleasure.

Ask your partner how they are feeling – They may be worried about hurting you or appearing too eager.

Take it slowly – It may be easier to start with cuddles or a sensual massage the first few times, rather than penetrative sex.

Plan ahead – Sex may be less unplanned after treatment because of needing to use vaginal lubricants or erection devices. Choose a time when pain and fatigue are at their lowest.

Explore different sexual practices – Some of the ways you used to enjoy having sex may be more difficult or not possible after cancer treatment. Keep an open mind about ways to feel sexual pleasure – 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, but be mindful if this is important to your partner. Spend time together doing something you both enjoy.

Try exploring your sexuality on your own – Self-stimulation (masturbation) can help you understand what's changed and what feels good, and you can then talk about this with your partner.

Use relaxation and meditation techniques – These can help you stay in the moment with your partner. Your treatment centre may run a program where you can learn such techniques, or may be able to direct you to organisations that run these programs.

Seek assistance – Talk to your doctor or ask for a referral to a sexual health physician or sex therapist to help you find solutions.

Be patient – Many people find that things often improve with time and practice.

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 girlfriend or boyfriend. These activities can feel especially challenging if you are dealing with changes to how you look or fertility issues, particularly if you haven't had much experience of sex.

As well as talking to your treatment team and possibly seeing a sex therapist, you could get in touch with CanTeen.

CanTeen offers counselling in person or by phone, email or instant messaging. CanTeen also runs online forums and camps. Visit canteen.org.au or call **1800 226 833**.

What words should I use?

You know you have to talk about it, but it's hard to know what to say. 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."

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

"I really miss our sex life. When should 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.]."

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

"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?"

Communicating with your partner

Problems can arise due to misunderstandings, differing expectations and different ways of adapting to changes. The key to adjusting to sexual changes after cancer is communication. If you have a partner, discuss how you're feeling, and your concerns and needs. Talk about ways you can adapt your sexual activities during and after cancer treatment. Even if you had a good relationship before the diagnosis and found it easy to share your thoughts, you may not have openly talked about sex in your relationship.

Common barriers to talking about sex during and after cancer treatment include: embarrassment; lack of time or privacy; fear of rejection; fear of getting cancer; and waiting for the other person to mention it.

While it can feel easier to avoid talking about sex when you are both coping with the demands of cancer and treatment, this can often lead to frustration and confusion, as neither of you will have your needs met. See table opposite for some ways to start talking to your partner. Let your partner know what you're going through and how they can help you cope. It could help to acknowledge that your relationship is changing and that you both need time to adjust.

It will also help to set aside time for intimacy. Plan to have a regular meal together or go for a walk. Try to focus on 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.

Communicating with a new partner

You may be worried about starting a sexual relationship with a new person in the future. It isn't easy to decide when to tell a potential sexual partner about any changes to your body (such as you've had a breast removed, had a breast reconstruction, need assistance having an erection 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 let a new partner know how cancer has changed your body when you feel ready. It may be easier if you practise what you want to say (see page 34) with someone and think about answers to questions they may ask. Start with small amounts of information and provide further details if they ask. You might want to show the other person how your body has changed before any sexual activity so that you can both get used to how that makes you feel.



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

- When you are ready for intimacy, start slowly and take your time. Talk to your partner about how you are feeling and how things may have changed for you.
- You might need to plan ahead for sex. Choosing your times carefully and being prepared can help you cope better with pain, fatigue, body image problems and other issues.
- If you find that you become distracted during sex, try learning mindfulness and relaxation techniques to help you stay in the moment.
- Use self-stimulation (masturbation) to help you explore how your body has changed and what makes you feel good.
- Speaking to a counsellor or sex therapist or to someone who has been in a similar situation can help you develop ways to adapt to sexual changes.
- Keep in mind that sexual attraction is usually a combination of emotional and physical attraction.

Starting a new relationship

If you are starting a new relationship, it may take some 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 problems discussed in this chapter are common among anyone with a cancer diagnosis, but some changes affect only females or only males, and others are caused by particular treatments. The changes may be temporary or ongoing.

Fatigue

It is common to feel tired and have no energy during and after cancer treatment. Your tiredness may continue for several weeks or months after treatment has finished, but this will vary from person to person. Fatigue can lead to a temporary loss of interest in sex and intimacy or you may need to take a less active role.



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 to spark your interest.
- Spend time being affectionate with your partner – hugging, kissing and holding hands are all ways of feeling close to your partner when you're too tired for sex.
- Try to be intimate at different times of the day.
- Speak to an occupational therapist about ways to manage your fatigue.
- Listen to our “Managing Cancer Fatigue” podcast at [cancercouncil.com.au/podcasts](https://www.cancercouncil.com.au/podcasts).

Sadness and depression

Depression is very common in people diagnosed with cancer, but it can be treated. It is natural to feel down at any stage during diagnosis and treatment. Changes to your body can be upsetting and it takes time to adjust. You may find that you have difficulty sleeping, lose interest in activities you used to enjoy, don't feel like eating, or lack energy. Your energy and desire for sex may also be low.

If you suspect that you, or someone you care for, may be depressed, you can find a depression checklist and helpful information at beyondblue.org.au or call 1300 22 4636. For 24-hour crisis support, call Lifeline 13 11 14 or visit lifeline.org.au.



Tips for managing low mood

- Do things that make you feel good, such as watching funny movies, going for a walk or having a massage.
- Get up at the same time every morning, regardless of how tired you feel. Avoid long naps during the day.
- Try to return to activities you enjoyed before you had cancer.
- Be as active as possible. Plan activities for each day such as exercise, spending time with other people, or reading.
- Ask your doctor if your mood change could be related to medicines, hormone changes or another illness. Depression is a common result of low levels of sex hormones.
- If you have continued feelings of depression, tell your doctor, as counselling and/or medicines – even for a short time – may help. Let your doctor know if sex is important to you, as some antidepressants can affect sexual function and libido.

Anxiety

Feeling anxious and scared is a normal reaction to a cancer diagnosis and its treatment. You might also be worried about having sex after treatment, concerned that it will hurt. As a result you may lose interest in sex and find yourself avoiding it.

You may feel less anxious if you find out more about your illness 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

- Ask your doctor if anti-anxiety medicine will help. Be aware that some medicines may lower your libido.
- Try mindfulness-based techniques, including deep relaxation and meditation. Relaxing your body and mind often helps you to feel more in control and able to cope with fear, tension and anxiety. Call **13 11 20** for copies of Cancer Council's meditation and relaxation CDs.
- If you feel like your thoughts are becoming negative and hard to control, consider cognitive behaviour therapy (CBT). This can show you how to change unhelpful patterns of thinking that might be getting in the way of a fulfilling sex life. A psychologist could help you learn CBT. You can also call **13 11 20** to ask about online CBT guides.
- Share your thoughts with your partner. It will show you trust them and help create intimacy.
- Consider having counselling to learn how to manage anxiety. See a social worker or psychologist.

Loss of sexual pleasure

During and after cancer treatment, some people find that although they can still have sex, they do not 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.

People who have had a body part such as a breast or prostate removed, may need to explore touch and stimulation to other parts of the body to feel ready for sex.



Tips for increasing your enjoyment of sex

- Consider touching, hugging and kissing. This is a chance to feel close to your partner without expectations of sexual penetration.
- Choose a time when you won't be disturbed and set the mood with soft lighting, candles and music.
- 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.
- Try using a personal lubricant with a water or silicone base, e.g. Pjur or Astroglide.
- If you are having difficulty reaching orgasm, see the tips on pages 46–47.
- Accept that you may not reach orgasm every time. Take the pressure off by focusing on giving and receiving pleasure in different ways.
- Use mindfulness techniques to help you stay in the moment with your partner. Call **13 11 20** for copies of meditation and relaxation CDs.

Loss of desire

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

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

- treatment side effects such as feeling tired and sick
- being too worried about the cancer to think about sex
- fear of pain during intercourse
- changes in your hormone levels after treatment
- 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 sex drive as you get older.

Adjusting to changes in sex drive can be emotionally and physically challenging for people with cancer and their partners. 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 or call Cancer Council 13 11 20 for contacts in your local area.

“ 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

- Discuss changes to your libido with your partner so they understand how you're feeling and don't feel rejected.
- Make it a priority to spend time with your partner. Arrange a "date" or even a weekend away.
- Enjoy other physical contact with your partner without having sexual intercourse 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.
- Create a sensual mood with soft lights and music, and dress in something that makes you feel sexy. These things may help you get in the mood for sexual activity.
- Keep an open mind. Read an erotic story, watch an erotic movie or explore the range of adult products that are available (e.g. personal lubricants and sex toys like dildos and vibrators). These may help spark your interest in sex or your partner can satisfy themselves, either alone or with you present.
- Stimulate yourself so you become aware of how you like to be touched.
- 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.
- 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.
- 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.

Erection problems

Trouble getting or keeping an erection firm enough for intercourse is called erectile dysfunction or impotence. While the quality of erections usually declines with age, it can also be affected by worrying about the cancer or damage to the nerves during surgery or radiation therapy.

Erectile dysfunction can sometimes improve. There are also many products to treat the problem, including penile injection therapy, penile implants and PDE5 inhibitor drugs (e.g. Cialis or Viagra), available by prescription. There are also herbal preparations, nasal sprays and lozenges that contain testosterone, but check with your treatment team before using any of these.

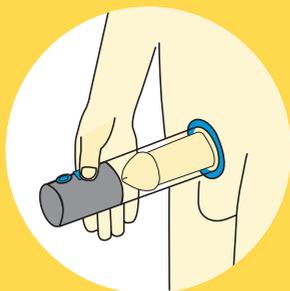


Tips for dealing with erection problems

- Help keep erectile tissue healthy while nerves heal from surgery by engaging in foreplay and other sexual activity with your partner.
- Try having sex with a half-erect penis. This may work best with the partner on top guiding the penis inside. This stimulation may encourage further and better erections.
- Help satisfy your partner and yourself without sexual penetration. Experiment with all-over touching, oral sex, masturbation or sex aids.
- Ask your doctor about other ways to keep your penis erect, such as tablets or injections (see opposite page), or get a referral to a specialist.
- If your cancer specialists say it is safe to use with your type of cancer, you could consider testosterone replacement therapy. This may help if you have low testosterone levels.

Ways to improve erections

There are several medical options available for trying to improve the quality of your erections. Ask your treatment team for more details about these methods.

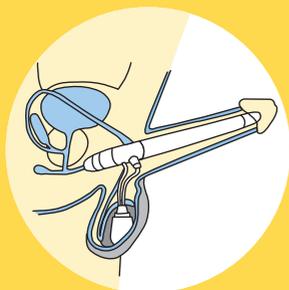


Vacuum erection device

A vacuum erection device (VED) or vacuum pump device uses suction to draw blood into the penis to make it firm and help maintain a natural erection.

Penile injection therapy

This has to be prescribed by a doctor. You will be taught to inject the penis with medicine that makes blood vessels in the penis expand and fill with blood, causing an erection. The erection usually lasts 30–60 minutes.



Implants

A penile prosthesis is inserted during surgery. Flexible rods or thin, inflatable cylinders are placed in the penis and connected to a pump in the scrotum. The pump is turned on or squeezed when an erection is desired.

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 males 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 orgasm 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. 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 55) 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.

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 a woman experiences orgasm. Emotional concerns can also affect orgasm.

Initially, you or your partner might feel that the activities listed below are not “real sex”, but it's possible to experience intimacy and sexual pleasure without penetrative intercourse.



Tips for reaching orgasm

- Use self-stimulation to find out what works for you.
- Try different ways of getting in the mood for intimacy: wear clothes that make you feel sensual, shower or bathe together, or have a weekend away if you can – whatever makes you feel sexy, relaxed and good about each other.
- 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 intercourse or while your clitoris is being stroked.
- Think about a past sexual experience or use erotic books, magazines or films.
- Set the mood or atmosphere with soft lighting, candles and soothing music.
- Consider using an electric vibrator, which may give you the extra stimulation you need to reach orgasm faster.
- Explore reaching orgasm without penetration. Try oral sex, masturbation with sex toys or all-over touching.

Changes to the vagina

Some cancer treatments may change the vagina, which can cause discomfort and/or pain during intercourse.

Shortening and narrowing of the vagina – Surgery may shorten the vagina, and radiation therapy to the pelvis can narrow the vagina. You may be advised to use a vaginal dilator after treatment ends. This is a tube-shaped device made from plastic or silicone. You insert the dilator into the vagina for short periods of time to gradually widen the entrance and prevent the side walls sticking together.

If you have any concerns about using a vaginal dilator, ask your health care team for a referral to a pelvic health physiotherapist.

Tight vaginal muscles – After cancer treatment, some women experience vaginismus, when the muscles around the vagina become tight. This is often caused by fear that intercourse will be painful, and can make penetration difficult. Ask your health care team for a referral to a pelvic health physiotherapist, who can help you learn how to keep the muscles relaxed during intercourse.

Vaginal dryness – A lack of oestrogen often causes vaginal dryness, which can make penetration during sex painful. You may also be more likely to get vaginal infections, such as thrush.

Thrush (candida) – 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.

Loss of sensation – Some women experience a loss of sensation in their vagina temporarily or permanently, depending on the type of treatment they have had. This can make sex uncomfortable or unsatisfying, or may cause low libido and arousal.

The table on the next two pages offers tips for coping with these vaginal changes.

Vaginal health

When treatment leads to changes in the vagina, women may need both vaginal lubricants and vaginal moisturisers to prevent discomfort and pain. Some women can also use oestrogen-based creams. Avoid products containing perfumes, oils or glycerine.

Vaginal lubricants (personal lubricants) – These are liquids or gels that are applied around the clitoris and labia and inside the vaginal entrance during sexual activity. You can buy water-based or silicone-based lubricants at supermarkets and chemists. Lubricants with a silicone base may last longer than the water-based ones. Petroleum-based products (e.g. Vaseline) are not recommended as they can increase the chance of developing a vaginal infection.

Vaginal moisturisers – These non-hormonal, over-the-counter products help to restore lubrication and the natural pH level to the vagina and vulva. They are usually used 2–3 times per week.

Vaginal oestrogen therapy – Pessaries or creams can help restore oestrogen levels in the vagina and relieve discomfort. These may not be an option if you are having hormone therapy for cancer.

Coping with vaginal changes

Short/narrow vagina

- Use personal lubricant to make intercourse comfortable. Choose a water-based or silicone-based gel that has no added perfumes or colouring (e.g. Pjur or Astroglide).
- Apply a non-hormonal vaginal moisturiser (e.g. Replens, Multi-gyn or Yes) several times a week to help keep your vagina lubricated.
- Try a vibrator or regular, gentle sexual intercourse. Experiment with different positions for penetration.
- Use a foam ring around the base of your partner's penis to reduce discomfort and pain during intercourse.
- Consider using a vaginal dilator 2–6 weeks after you've finished radiation therapy to widen your vagina. Using dilators can be challenging and some people feel like giving up. If you need support, call Cancer Council **13 11 20** and ask to speak to someone who has used a dilator after cancer treatment.

Vaginal dryness

- Avoid soap, bubble bath and creams that can irritate your genitals.
- Use a non-hormonal vaginal moisturiser several times a week.
- Talk to your doctor about whether oestrogen creams or pessaries are an option with your type of cancer.
- Apply lubricant as part of your sexual foreplay. Choose a water-based or silicone-based gel that has no added perfumes or colouring (e.g. Pjur or Astroglide).
- To help with sexual arousal, take more time before and during penetration to help the vagina relax and become well lubricated.



Thrush

- Seek medical advice to rule out other types of vaginal infections.
- Treat thrush with prescription creams or medicines.
- Wear loose, cotton clothes. Avoid nylon pantihose, 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 a diet low in sugar and yeast.

Loss of sensation

- 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 see whether this 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 enjoyed having sex in are now uncomfortable or you may be worried about hurting your partner. The medicines you are taking may make you feel drowsy and tired, which may affect your libido.

👏👏 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 just try and get into a comfortable position with the pillows around you. 🗣️🗣️ *Annmaree*

Painful intercourse

Irritation of the prostate or urethra from surgery or radiation therapy can cause painful orgasms. If you have developed scar tissue in the penis after surgery, this may cause pain or bleeding, but it usually settles down in time. Anal sex can be painful after radiation treatment for prostate or anal cancer.

Pelvic surgery, radiation therapy or treatment that affects hormones can reduce the size or moistness of the vagina, which can make intercourse painful. Fear of pain can cause the muscles around the vagina to become tight (vaginismus), and this can make penetration difficult or impossible.



Tips for managing pain

Managing pain

- Plan sexual activity for the time of day when your pain is lowest. If you are using pain medicine, take it shortly before sex 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.
 - Use relaxation techniques such as warm baths or massage to relax you before having sex.
 - If pain continues, you can ask to be referred to a specialist pain clinic. It is important to deal with pain early as a holistic approach is important for long term benefits.
- See our *Overcoming Cancer Pain* booklet and listen to our “Managing cancer pain” podcast.

Making penetrative sex more comfortable

- Avoid deep pelvic thrusts – choose alternative positions to control the depth of penetration.
- Use plenty of water-based or silicone-based lubricant, e.g. Pjur or Astroglide.
- Try to be close to orgasm 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 50) and pelvic floor exercises to help manage painful intercourse.
- Ask an occupational therapist what products can assist with positioning – they may suggest using wedges, pillows, electric beds, 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. The pelvic floor muscles that affect bladder and bowel control also affect sexual function and arousal. Having bladder or bowel issues can make you feel embarrassed and impact your sexuality, but there are ways to manage symptoms.

Incontinence can be temporary or permanent. For advice and suggestions on managing incontinence, call the National Continence Helpline on 1800 330 066, or visit bladderbowel.gov.au.

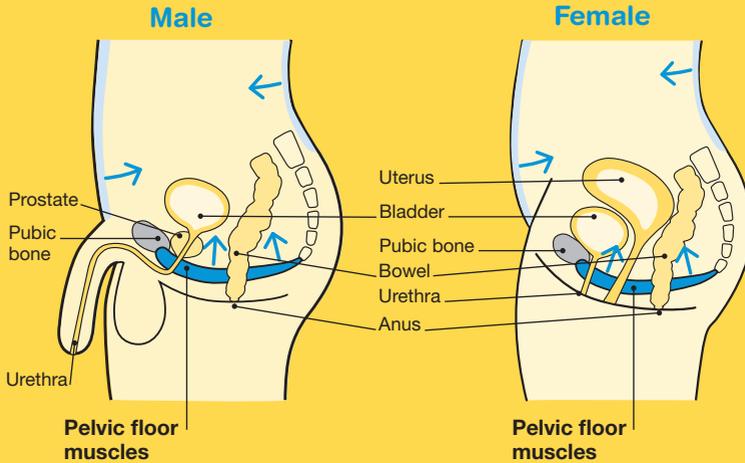


Tips for managing bladder and bowel issues

- 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 having sex.
- Use plugs designed 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.
- Cover your bed with large, fluffy towels.
- Women only: talk to your doctor about whether oestrogen inserted into the vagina as a cream or tablet could improve things. This may not be an option if you are having hormone therapy.
- Try positions that reduce pressure on the bladder such as being “on top”.
- See a pelvic health physiotherapist for advice.

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.



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. Try to hold the contraction for up to 10 seconds. Relax your muscles slowly after each hold.

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

It's common to feel anxious about the physical changes caused by treatment, including: loss of hair from the head and body; weight loss or weight gain; skin rashes; removal of a body part and use of a prosthesis (see pages 58–59); swelling of part of the body (lymphoedema); having a stoma (see page 60); and scars.

Some cancers of the head and neck can cause significant changes to the way you speak, 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 appearance may make you feel less attractive, and this can affect your sexual confidence, self-esteem and body image. You may worry about other people's reactions to you. It takes time to adjust to changes in appearance.

Look Good Feel Better program

This free two-hour program teaches men, women and teens how to use skin care, hats and wigs to help restore appearance and self-esteem during and after treatment. Call 1800 650 960 or visit lgfb.org.au for more information and to book into a workshop.

“ My sexual partner has always wanted to have sex with me – this made me feel good about myself after my surgery and when my head was shaved. He didn't care – he just loved my body anyway. ” *Daphna*



Tips for adjusting to appearance changes

- Be gentle with yourself and acknowledge how you are feeling.
- Look at and touch your scars so you get used to the changes.
- Give yourself time to get used to any physical changes. Some changes may be temporary and will improve with time.
- Focus on yourself as a whole person and not just the part of you that has changed.
- Remember that sexual attraction is based on a mix of emotional and physical factors, not on a single body part or another physical characteristic.
- Use clothing, make-up or accessories to highlight your best features.
- Choose well-fitting clothes. Wearing something too tight or too baggy will draw attention to your weight loss or gain.
- 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** to ask about a wig service in your area.
- Show your partner any body changes before sexual activity. This may allow both of you to get used to how the differences make you feel.
- If you feel uncomfortable about a part of your body, you can wear clothes to cover it during sex – e.g. if you've had breast surgery you may choose to wear a camisole. You may also prefer to avoid sexual positions that leave the area exposed.
- Dim the lights when you have sex until you feel more confident about your body.
- Talk to your doctor about the possibility of plastic surgery or a facial prosthesis if you have had a significant change in your facial appearance from surgery or radiation therapy. This may help you regain a more natural appearance and help with changes in speech.
- 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. It will take time to get used to how your body and body image have changed. All this can affect your sexual desire and your sexual confidence. Try to remind yourself that you are loved for who you are, not for your particular body parts. For ideas and information on restoring body image, see pages 56–57.

People who've had a breast or testicle removed may want to consider a prosthesis to improve appearance and self-esteem. This is a personal decision. Your specialist can give you more detailed information about your options and what the procedure involves.

Men who have sex with men

Men who have sex with men may face particular issues after some types of surgery. If the prostate is removed, there may be reduced sexual pleasure and arousal during anal penetration. Research shows that gay and bisexual men can find these changes particularly difficult to come to terms with.

The removal of the anus is a major change, but many men still enjoy other types of sexual activities. However, intercourse via the stoma can be dangerous, and sexually transmitted infections can be passed on through the stoma.

For more information visit the Prostate Cancer Foundation of Australia's website, prostate.org.au, and download the information pack for gay and bisexual men.



Tips for adjusting to 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. Also show your partner the body changes. Accept that it may take time to feel comfortable about your body again.
 - 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 56) at **lgfb.org.au** or call **1800 650 960**.
 - Talk to a sexual health physician or sexual therapist about the ways any change to your body may be affecting your sex life and relationship. See **societyaustriansexologists.org.au** to find an accredited sexologist near you.
- See our *Breast Prostheses and Reconstruction* booklet.

Adapting to life with a stoma

Some types of surgery for bowel or bladder cancer create a stoma – an opening in the abdomen that allows faeces or urine to flow through and be collected in a small plastic bag. Often 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 before intercourse. If you prefer, cover your bag with fabric or a cummerbund to prevent the plastic clinging to your skin.
- Wear clothing that makes you feel good – a mini-slip, short nightgown or nightshirt, specially designed underwear or boxer shorts.
- Have 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.

“ 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*

Adapting to life after a brain tumour

As brain tumours do not directly affect sexual organs, you might not expect that your sexuality will be affected. But the brain is an important sexual organ responsible for sexual urges, thoughts and behaviours.

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

Common changes in sexuality after a brain tumour include:

- loss of libido or sexual drive (see pages 42–43)
- inability to achieve or maintain an erection (see pages 44–45)
- difficulty or inability to orgasm (see pages 46–47)
- premature ejaculation
- talking a lot about sex or inappropriate touching (disinhibition)
- having an increased desire for sex (hypersexual)
- weakness in arm or leg, or slow and uncoordinated movements.

If you have become more uninhibited or hypersexual after surgery, you may find that your family and friends ask you to masturbate in private and not to make inappropriate sexual comments.

Early menopause

Menopause occurs when your ovaries stop working and you have not menstruated for one year. This means you will not be able to fall pregnant naturally. For most females, this happens naturally between 45 and 55. Most menopause symptoms are related to a drop in your body's oestrogen levels. These 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.

Early menopause (or 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 (known as osteoporosis or osteopenia).

The loss of menstruation and fertility 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 less attractive.

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



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 to help reduce stress and lessen symptoms.
 - Talk to your doctor about the benefits and risks of hormone replacement therapy (HRT) to treat menopausal symptoms.
- There are also non-hormonal options, such as acupuncture, that you could try.
- Ask your GP to arrange a bone density test to check for osteoporosis/osteopenia, which can develop after menopause.
 - Eat high-calcium foods and/or take a calcium and vitamin D supplement, and exercise regularly to strengthen your bones and help reduce the rate of bone loss. Osteoporosis Australia has more information – visit osteoporosis.org.au or call **1800 242 141**.

If your uterus is removed (hysterectomy) but one of your ovaries remains, you will no longer have monthly periods or be able to carry a child, but you will continue to produce oestrogen and can still 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 50–51 for information about fertility issues. See also *Coping with vaginal changes* on pages 50–51 for tips on coping with a dry vagina caused by menopause.

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 treatment starts about your risk of infertility and ways to preserve your fertility. It may be possible to store your eggs 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 additional children, and you may worry about the impact of this on your relationship or future relationships. Even if your family is complete or you weren't planning to have children, you may experience strong emotions.

As well as talking with your partner, it may help to talk with a counsellor, sex therapist, oncologist, urologist or oncology nurse.

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 have children naturally.

Depending on the type of chemotherapy drugs used and the dose, periods may become irregular but often return after treatment ends. In some cases, periods stop permanently and lead 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 men may not get strong erections again. If the problem is ongoing, ask your doctor about storing 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 the production of sperm and affects 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.
- See our *Fertility and Cancer* booklet.



Key points about specific challenges

Talk openly

Communicating openly with your partner may help you overcome any sexual problems caused by cancer treatment.

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 is 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 may make some of your usual sexual practices and positions uncomfortable or painful. Try to have an open mind about exploring some 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.

If you find that the changes after cancer are getting in the way of a fulfilling sexual life, talk to your GP or cancer specialists about seeing a sex therapist.



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. going away for a night or two) 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 be that your partner seems to have 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. Over time, you both might get used to a relationship without intimacy or sex, assuming that this is the new way of living or “new normal”.

Ways to communicate

Communicate openly – This will be more important than ever. It may help you avoid frustrations that can arise from misunderstandings. If you and your partner have never talked much about sex before 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 such 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, touching, holding, hugging and massaging can help you feel close with your partner and show you love them 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. 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.

👤👤 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 three weeks?', and I'm a fairly tactile person. 👤👤 *Ian*

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 and your partner have been through a difficult and confronting experience and allow yourselves time to adjust.

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

- See our *Caring for Someone with Cancer* booklet and listen to our "Cancer Affects the Carer Too" podcast.

Safety concerns for partners

- Be assured that it is not possible for your partner to transmit cancer through intimate activities such as kissing or intercourse.
- Sexual activity will not make cancer spread, nor will it make the cancer come back.
- Chemotherapy drugs may stay in your partner's body fluids for some days. Using condoms or other barrier methods (see page 27), if having any type of sex after treatment, can protect you from any potential risk. Your treatment team can give you more details about how long you need to use protection.
- Some chemotherapy drugs can be passed into body fluids such as saliva. Ask your 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 once 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 treatment team will be able to advise you.
- 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 have to avoid sex for 48 hours after each treatment, and then use condoms or other barrier methods during the rest of the treatment cycle and for six weeks after the final treatment.
- Speak to the health care team if you need more information.



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.

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 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 feel like I 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 depending on where you live.

Cancer Council 13 11 20

Trained professionals will answer any questions you have about your situation and link you to services in your area (see inside back cover).



Information resources

Cancer Council produces booklets and fact sheets on over 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 (see back cover).

Practical help

Your local Cancer Council can help you find services or offer guidance to manage the practical impact of a cancer diagnosis. This may include access to transport and accommodation services.



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.

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 Australia	canceraustralia.gov.au
Cancer Council Online Community	cancercouncil.com.au/OC
Carer Gateway	carergateway.gov.au
Carers Australia	carersaustralia.com.au
<i>The Thing About Cancer</i> podcast	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
Beyond Blue	beyondblue.org.au
Bladder and Bowel	bladderbowel.gov.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	pelvicpain.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 sexuality?
- What can be done to preserve sexual functioning and pleasure?
- 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 are they likely to last? Are any changes likely to be 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?

Side effects

- What sort of problems might we experience during intercourse?
- It hurts when we have intercourse. 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?
- If I've had a sexually transmitted infection, will it come back with chemotherapy?
- 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?
- Can I give cancer to my partner if we have sex?
- Are there any complementary therapies I could try? Are there any over-the-counter products I should avoid?
- Can you refer me to a sex therapist?

Questions for females

- Will I still experience the same sexual sensations after having this treatment?
- Will hormone replacement therapy be necessary? Or beneficial?
- I have vaginal dryness. What do you recommend?
- Is it safe to use an oestrogen cream?
- How can I stretch my vagina?
- How can I manage the symptoms of menopause?
- I want to have sex but I have no sexual thoughts and find it hard to feel aroused. What can I do?

Questions for males

- 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?
- I want to have sex but I have no arousal or sexual thoughts. What can I do?



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 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 radioactive material is placed into or near the cancer.

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 that connects 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.

cystoscopy

A procedure that uses a cystoscope, a thin tube with a light and a camera, to examine the vagina, cervix, bladder or rectum. It can remove tissue samples or small tumours.

cytotoxic drug

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

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 two 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.

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.

genitals

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

gynaecological cancers

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

hormone replacement therapy (HRT)

Drug therapy that supplies the body with hormones that it is no longer able to produce naturally. Often used to treat the symptoms of menopause.

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 and the cervix.

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 or faeces.

infertility

Difficulty conceiving after trying for 12 months, or 6 months if over 35.

intimacy

Being physically and emotionally close to someone.

labia majora

The outer lips of the vulva.

labia minora

The inner lips of the vulva.

LGBTI

A commonly used acronym for people who identify as lesbian, gay, bisexual, transgender, intersex.

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

mons pubis

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

oestrogen

The primary female sex hormone. It is produced mainly by the ovaries and helps regulate the female reproductive cycle.

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 placed in the penis to mechanically create an erection.

perineum

The area of skin between the vulva (or, for males, the scrotum) and the anus.

premature/early menopause

Menopause that occurs before 40.

premature ejaculation

The inability to delay ejaculation.

premature ovarian insufficiency (POI)

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

progesterone

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

prostate

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

prostatectomy

Surgery to remove all or part of the prostate gland.

prosthesis

An artificial replacement 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 fluid from the prostate and seminal vesicles.

seminal vesicles

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

sex

Penetrative intercourse and other activities such as oral sex, self-stimulation.

sexual arousal

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

sexual desire

Wanting to have sex.

sexuality

How people express themselves as sexual beings.

sexual response cycle

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

side effect

Unintended effect of a drug or treatment.

sperm

The male sex cell.

stoma

A surgically created opening to the outside of the body.

targeted therapy

Treatment that attacks specific particles (molecules) within cells that allow cancer to grow and spread.

testicles

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

testosterone

Major male sex hormone produced by the testicles. Testosterone promotes the development of male sex characteristics.

transgender

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

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 woman. 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
- cancersa.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.
2. LA Brotto, M Yule & E Breckon, “Psychological interventions for the sexual sequelae of cancer: a review of the literature”, *Journal of Cancer Survivorship*, vol. 4, iss. 4, 2010, pp. 346–60.
3. E Gilbert, J Perz & JM Ussher, “Talking about sex with health professionals: the experience of people with cancer and their partners”, *European Journal of Cancer Care*, vol. 25, iss. 2, 2016, pp. 280–93.
4. J Perz, JM Ussher et al., “Feeling well and talking about sex: psycho-social predictors of sexual functioning after cancer”, *BMC Cancer*, vol. 14, no. 228, 2014, pp. 22–47.
5. JM Ussher et al., “Threat of sexual disqualification: the consequences of erectile dysfunction and other sexual changes for gay and bisexual men with prostate cancer”, *Archives of Sexual Behaviour*, vol. 46, iss. 7, 2017, pp. 2043–57.



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 cancer nurses 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.

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



If you need information in a language other than English, an interpreting service is available. Call 13 14 50.

If you are deaf, or have a hearing or speech impairment, you can contact us through the National Relay Service. www.relayservice.gov.au



Visit your local Cancer Council website

Cancer Council ACT
actcancer.org

Cancer Council NSW
cancercouncil.com.au

Cancer Council NT
nt.cancer.org.au

Cancer Council Queensland
cancerqld.org.au

Cancer Council SA
cancersa.org.au

Cancer Council Tasmania
cancertas.org.au

Cancer Council Victoria
cancervic.org.au

Cancer Council WA
cancerwa.asn.au

Cancer Council Australia
cancer.org.au

*This booklet is funded through the generosity of the people of Australia.
 To support Cancer Council, call your local Cancer Council or visit your local website.*