

LGBTQI+ People and Cancer

A guide for people with cancer, their families and friends



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

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

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We thank the many consumers, health professionals and organisations who reviewed this booklet. For a full list of reviewers, see page 79.

Note to reader

Always consult your doctor about matters that affect your health. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for medical, legal or financial advice.

You should obtain independent advice relevant to your specific situation from appropriate professionals, and you may wish to discuss issues raised in this book with them.

All care is taken to ensure that the information in this booklet is accurate at the time of publication. Please note that information on cancer, including the diagnosis, treatment and prevention of cancer, is constantly being updated and revised by medical professionals and the research community. Cancer Council Australia and its members exclude all liability for any injury, loss or damage incurred by use of or reliance on the information provided in this booklet.

Cancer Council

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



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



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About this booklet

This booklet has been prepared to help you understand how cancer and its treatment may affect LGBTQI+ people – lesbian, gay, bisexual, transgender, queer, and other diverse sexualities and genders, as well as people with intersex variations.

Many people feel shocked and upset when told they have cancer. You may have specific concerns or questions about how your sexual orientation, gender, and/or sex characteristics will affect your treatment and your interaction with health professionals.

This information may answer some of your questions and help you think about what to ask your treatment team (see page 73 for a question checklist). We also include information about support services.

This booklet does not need to be read from cover to cover – just read what is useful and relevant to you. Some terms that may be unfamiliar are explained in the glossary (see page 74). You may also like to pass this booklet to family and friends for their information.

How this booklet was developed – This information was developed with help from LGBTQI+ organisations, health professionals and LGBTQI+ people affected by cancer. It is based on the *Out with Cancer* study into diverse sexualities, genders and sex characteristics.¹⁻⁴



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

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Key to icons

Icons are used throughout this booklet to indicate:



More information



Tips

LGBTQI+ people and cancer

From diagnosis to treatment and beyond, the experience of having cancer is different for everyone. It affects every aspect of your life, including the way you look and feel, how you have sex and if you can get pregnant.

Extra challenges may include physical changes that impact your sense of identity, and practical issues such as getting appropriate cancer screening and hospital care. Support networks may be different because of limited contact, or no contact, with family of origin. Instead, you may rely on close friends (chosen family) for support.

Many LGBTQI+ people have experienced discrimination and had other negative experiences throughout their lives because of their sexual orientation, gender and/or sex characteristics. If you have experienced discrimination or been refused health care in the past, this may mean you do not feel safe seeking health care or disclosing information needed for treating cancer holistically.

This booklet discusses how to manage these practical, physical and emotional issues, and ways to find inclusive cancer care.



In Australia, about 151,000 people are diagnosed with cancer every year (excluding common skin cancers).⁵ It is estimated that LGBTQI+ people make up 5% of Australia's population. This means it's likely that over 7500 LGBTQI+ people are diagnosed with cancer each year, and approximately 23,000 are cancer survivors.

Challenges you might face

Research shows that as an LGBTQI+ person diagnosed with cancer you may have to deal with a number of unique challenges, including:

- health professionals making assumptions about your sexual orientation, gender and sex characteristics, which can make you feel invisible
- anxiety about coming out as LGBTQI+ and fear of negative reactions from health professionals (see the *Coping with Cancer* chapter, page 16)
- higher levels of depression and anxiety because of a history of marginalisation, violence, stigma, exclusion and discrimination (sometimes called minority stress)
- difficulty having your partner/s or other significant people recognised as your family
- less or no support from your family of origin
- little or no LGBTQI+ specific cancer information or support
- lack of knowledge among health professionals about issues specific to LGBTQI+ people.

Cancer screening for LGBTQI+ people

Screening is organised testing to find cancer before any symptoms appear. Finding cancer early and when it hasn't spread often makes it easier to treat. In Australia, there are screening programs for breast, cervical and bowel cancer. Most people who are in a certain age group and who have a Medicare card, will receive an invitation in the mail to get screened.

LGBTQI+ people may face several barriers to screening (see next page).

Ask your doctor what screening tests are right for your body. It is now possible to collect your own sample for the cervical screening test. This needs to be done at the doctor's office. For more information on screening, visit canwe.org.au or transhub.org.au/cancer-screening.

LGBTQI+ people and cancer risk

The causes of many cancers are unknown, but some factors may increase the risk if you're LGBTQI+. Risk factors for intersex people depend on their specific variation. Cancer risk has often been used as a reason for medical treatment of intersex people during childhood (see page 56).

Delaying or avoiding cancer screening – Research shows that many LGBTQI+ people delay or avoid screening. This may be because they think mammograms or cervical screening are not for them because of who they have sex with. Trans people may find screening uncomfortable and upsetting. Trans, gender-diverse and intersex people may not receive appropriate screening reminders. Missing screening tests may mean cancer is diagnosed at a later stage when it is harder to treat.

Higher risk for smoking- and alcohol-related cancers – Studies show that there are higher rates of smoking and drinking alcohol among some LGBTQI+ people, often because of minority stress. These factors increase the risk of several cancers including breast, mouth, and bowel cancer. Smoking also increases the risk of lung and cervical cancers.

Higher risk of HPV (human papillomavirus) – This very common sexually transmitted infection causes many types of cancer, including cervical, anal, throat (oropharyngeal), penile, vulvar and vaginal. HPV can be passed on sexually, including by fingers and oral sex, or through sharing sex toys. The HPV vaccine can protect against the virus. For more information, visit hpvaccine.org.au and thebottomline.org.au.

Living with HIV – Living with HIV/AIDS may make you more likely to develop some cancers. These are known as AIDS-defining cancers and include Kaposi sarcoma, aggressive B-cell non-Hodgkin lymphoma and cervical cancer. Some cancers are common in people living with

HIV but are classified as non-AIDS-defining. They include anal, liver, oral cavity and pharynx and lung cancers, and Hodgkin lymphoma.

Lower rates of pregnancy – Pregnancy before age 30, breastfeeding and using oral contraceptives may all offer some protection from breast cancer and gynaecological cancers. Lesbian, bisexual and trans people are statistically less likely than cisgender heterosexual women to have a child before age 30. If you haven't had children, you may not have breastfed or had a break in your menstrual cycle.

Language and terms used in this booklet

The words used to describe sexual orientation, gender and sex characteristics change constantly, and you may not use the terms we've used in this booklet.

Sexual orientation – How a person thinks about their sexual identity, how they behave and the people they are attracted to. Examples include heterosexual, gay man, lesbian, bisexual, pansexual and asexual.

Gender – Whether a person is a man, woman, agender, genderqueer, genderfluid, or a combination of one or more of these things. Gender can be binary (man or woman) or non-binary. Gender may align with the sex assigned for a person

at birth (cisgender) or it may be different (transgender).

Sex characteristics – This refers to a person's physical characteristics, including genitals, gonads (ovaries and testicles), reproductive organs, hormonal patterns and chromosomal patterns. Sex characteristics can change over a person's lifetime and may be different from the sex assigned at birth.

Intersex – This is an umbrella term used to describe innate bodily variations in sex characteristics that don't match the typical understanding of female or male bodies. Older terms for intersex variations include differences or disorders of sex development.

Key questions

Q: Do I need to tell my cancer care team that I am LGBTQI+?

A: Knowing more about you and how your past experiences have affected your health, including issues around past trauma, sexuality, fertility and carer support, can help your cancer care team provide safe care that is appropriate to your situation. It also makes it easier to recognise and include same-gender partners (see *Coping with cancer* on page 16 for more information).

You deserve cancer care that meets your needs. Person-centred care is care that treats you in the way you'd like to be treated and listens to your needs, preferences and values, as well as the needs of your family and carers. It means that you are an equal partner with your health care provider in planning your treatment and ongoing care (known as shared decision-making).

As part of person-centred care, it is important you feel comfortable and confident with your cancer care team. However, research shows that many LGBTQI+ people do not disclose their sexual orientation, gender or sex characteristics to health professionals for fear of discrimination or harassment.



Much of this booklet focuses on the experience of people with marginalised sexualities and gender identities. Intersex people who are cisgender and heterosexual may prefer to read information specific to intersex people on pages 54–58 and then refer to Cancer Council's general cancer information resources. General information is also available from Intersex Human Rights Australia. Visit ihra.org.au.

Q: What details could I disclose?

A: Many health professionals are experienced in talking about health issues confidentially. If the information is not already on your medical records and you think it is relevant to your cancer care, you may want to tell them about your:

- sexual orientation
- gender
- pronouns
- variations of sex characteristics
- medical history such as past surgeries, being on hormone blockers, hormone replacement therapy or taking gender-affirming hormones
- concerns about preserving fertility
- concerns about sex and intimacy
- any history of trauma, including medical trauma.

You may be reluctant to disclose these details, especially if previous bad experiences have affected your trust in health professionals or you are not “out” in all areas of your life. But being open and honest with your cancer care team:

- helps them consider all possibilities when trying to diagnose the cause of your symptoms (such as ovarian cancer in a trans man)
- ensures they have all the information they need to offer informed and safe care for you
- means they can connect you with support services that are right for you and your family.

Ultimately, it is up to you to decide how much information you share with others. You may choose to tell only health professionals you see regularly for treatment or check-ups. See *How to come out to your health professionals* on pages 22-23 for more information.

Q: What can I expect as an LGBTQI+ person with cancer?

A: In Australia, everyone has the right to safe and competent health care; the right to be free from unlawful discrimination (see page 24); the right to accept or refuse treatment; and the right to privacy and confidentiality.

This means your health providers should:

- respect your body, sexual orientation and gender
- respect your partner/s and family
- listen to and respect your treatment goals
- respond to your care needs, preferences and values
- involve you in decisions about your treatment and ongoing care
- only collect or disclose your health information to others with your consent, or as required by law.

After a diagnosis of cancer, you need to make many decisions. To help you get the best outcome, it is important that you take an active role in your care and feel able to ask questions.

If you are concerned about the security of your health information, talk to your health provider or ask to see a copy of their privacy policy. For more information, visit the Office of the Australian Information Commissioner at oaic.gov.au.

▶ See our *Cancer Care and Your Rights* booklet.



Each person's experience of cancer is different, depending on the type of cancer, whether it has spread, their age and general health. Call Cancer Council 13 11 20 for free booklets and information about different cancer types and their treatments, or download copies from your local Cancer Council website.

“I was completely open about being a lesbian with a life partner and two children. My wife, Melissa, was acknowledged and respected by my doctors and the team. This openness was important because I became very ill during treatment and lost the capacity to speak.” JULIE (LESBIAN, OROPHARYNGEAL CANCER)

Q: What can my family and carers expect?

A: Your family may include your partner, children, chosen family, or family of origin.

The *Carer Recognition Act 2010* (Commonwealth) states that all carers have the same rights, regardless of sexuality or sex. All state and territory governments have also passed their own Act and policies. This means that when carers access services and are at work, they have the right to:

- be treated with respect and considered as a partner by healthcare workers or providers
- privacy and confidentiality
- not be discriminated against at work because they are a carer
- ask for flexible working arrangements
- take leave when caring for family or household members.

Partners or carers of LGBTQI+ people may face discrimination or lack of recognition of their relationship. Your cancer care team may assume a partner is a friend and exclude them from discussions and decisions about your care, and instead talk or look to your family of origin. If this is happening to you, see *How to deal with discrimination* on page 25.

All people who are married or live together as a de facto couple have the same rights. This means your spouse or partner/s can be involved in decisions about your treatment (see pages 62–63). In Australia, the term next of kin means a person’s spouse, domestic partner or closest living relative who is over 18 years of age. See also the *Caring for someone with cancer* chapter, pages 67–68.

Q: How can I find LGBTQI+ friendly cancer services?

A: LGBTQI+ friendly health services create an environment that feels safe and is supportive, respectful and non-judgemental. They don’t make assumptions about pronouns, your body, partners and families of choice. This is known as culturally safe care.

Connecting with a health service that focuses on the needs of LGBTQI+ people will mean you can trust them to support you. They should include anyone you wish to be part of your care plan, including your partner/s, family or chosen family.

Where you live might affect availability of LGBTQI+ friendly health services. Finding services that are welcoming and inclusive may be more difficult in regional and rural areas. You have the right to go somewhere else if you don’t feel comfortable with the service.

“It’s great that clinics, doctors, surgeons and so on actually have ways of displaying their friendliness and openness such as the gay flag on the front door. We need to see visual signs to give us that comfort.” RODNEY (GAY MAN, SKIN CANCER)

How to spot an LGBTQI+ friendly service



Look for signs of inclusion

These can include LGBTQI+ flags, rainbow ticks, posters and photos or statements about the service's commitment to LGBTQI+ communities. You may find these on the service's website or in their window or waiting rooms.



Find out about their experience and policies

Call or email the service to ask if they regularly see LGBTQI+ people and have an anti-discrimination policy. You could ask if any of their staff are LGBTQI+. It may be easier for a friend or family member to ask these questions.



Ask for recommendations

Your friends may know of services that are LGBTQI+ friendly. Ask what they liked and didn't like. If you have an LGBTQI+ friendly GP, ask them to refer you to a supportive cancer specialist.



Use DocDir website

This website lists doctors and mental health professionals who are welcoming and safe for LGBTQI+ communities, and knowledgeable about their unique health needs and concerns. Visit docdir.org.au.



Check forms and website

Before your appointment, check whether intake forms ask about sexual orientation, gender and intersex variations, and pronouns. Check the website for inclusive language and details about training or accreditation.



Trust your judgement

Sometimes you might just have a feeling about whether a health professional or service will be right for you. It's okay to trust your instincts.

Q: What can I do if I don't feel comfortable with my cancer care team?

A: Finding health professionals you trust is important at all stages, from diagnosis and treatment to follow-up care. You shouldn't miss out on treatments, help with side effects, or follow-up appointments because you've had a bad experience in the past.

You may feel that everything is happening too fast and that you don't have the time to get a second opinion. Check with your cancer specialist how soon treatment should begin and how much time you have to make decisions. You can get a second opinion or change your doctor even if you have started treatment.

If you are treated as a public patient in a public hospital, you will be seen by the specialist/s appointed by the hospital. If you have concerns, you may be able to talk to the head of the department, a patient representative or a patient advocate. Some hospitals have an LGBTQI+ patient navigator. This person provides culturally-safe support to LGBTQI+ people and advises health professionals about inclusive care. Look for their details on the hospital's website. To find organisations that may help you navigate the health system as an LGBTQI+ person, visit qlife.org.au/resources/directory.

You have the right to make a complaint about any aspect of your health care. This applies whether you are treated in a public or private hospital or treatment centre, or if you see a practitioner in a private clinic. You can usually find details about the complaints process on the health care facility's website. You can also check with the cancer care coordinator, nursing unit manager or social worker, or one of the nurses looking after you. If you are unhappy about the ethical or professional conduct of a health service

provider, you can contact the health complaints organisation in your state or territory.

If you think you have been discriminated against because of your sexual orientation, gender or intersex variation, see our *Dealing with discrimination* chapter (see pages 24–26).

Q: Where can I get support?

A: Most people going through cancer find it helpful to have support from others. This can include your family, friends or wider community. You might lean on your partner/s or chosen family for support and comfort, particularly if you have limited or no contact with your family of origin. Not everyone feels they need support from others; some people are happy to manage alone.

Ways to find support include:

- Speak to your general practitioner (GP), social worker, psychologist and other health professionals. They can link you with local services. See page 13 for ways to identify an LGBTQI+ friendly support service.
- Contact QLife on 1800 184 527 or visit qlife.org.au to connect with others in a safe space.
- Use the member directory compiled by LGBTQI+ Health Australia to find good sources of support. Visit lgbtiqhealth.org.au.
- Chat with other young people aged 12–25 diagnosed with cancer at canteenconnect.org.
- Call Cancer Council 13 11 20 or visit the Online Community at cancercouncil.com.au/OC.
- Get practical and financial assistance (see pages 69–72).
- ▶ See our *Emotions and Cancer* booklet.

Coping with cancer

A diagnosis of cancer can be difficult for any person to deal with. Research has shown that the outcomes of cancer and its treatment can be different for LGBTQI+ people (see pages 4-7).

How you might feel

After a cancer diagnosis and throughout treatment, it's common to feel a range of strong emotions including anger, fear, anxiety, sadness, grief and resentment. Research shows that LGBTQI+ people have a greater risk of mental and emotional distress after a cancer diagnosis for several reasons. You may feel anxious about coming out to health professionals, fear being discriminated against because of your sexual orientation, gender or intersex variation, or worry about how cancer and its treatment will affect your identity or relationships.

Some people have faced stigma and shame for being LGBTQI+, and may blame themselves for getting cancer or feel judged by others.

It's natural to feel vulnerable while having cancer treatment. If you are distressed, anxious or depressed, appropriate support and information is available (see pages 71-72).

► See our *Emotions and Cancer* booklet.



Pets can be an important part of the lives of many people. Talk to your local RSPCA to see whether they have a program that can help keep you and your pet together. If you are in hospital for an extended period, ask the ward staff whether you can organise a visit from your pet.

Dealing with feelings of sadness

If you have continued feelings of sadness, have trouble getting up in the morning or have lost motivation to do things that previously gave you pleasure, you may be experiencing depression. This is quite common after a cancer diagnosis.

Everyone has their own way of coping with their emotions. There is no right or wrong way. It is important to give yourself, and those around you, time to deal with the strong emotions that cancer can cause. For support, call Cancer Council 13 11 20. People aged 12–25 can also call Canteen on 1800 835 932.

If you think you may be depressed, talk to your GP, because counselling or medication – even for a short time – may help. Some people can get a Medicare rebate for sessions with a psychologist. Cancer Council may also run a counselling program in your area.

To connect with LGBTI peer support, call QLife on 1800 184 527 or visit qlife.org.au. For information about coping with depression and anxiety, call Beyond Blue on 1300 22 4636 or visit beyondblue.org.au. For 24-hour crisis support, call Lifeline 13 11 14 or visit lifeline.org.au.

Diversity of experience

As well as their sexual orientation, gender and sex characteristics, each person is shaped by their age, race, language, culture, spirituality, disability, education, relationships and financial situation, plus where they live and any previous experiences with the health system.

These factors can overlap to affect health and wellbeing, as well as cancer care. Aside from discrimination for being LGBTIQI+, some people may also have had to deal with ageism, sexism, racism or disability discrimination. Other people may find it difficult to merge different aspects of their identity (e.g. being young, trans) or work out how to communicate their needs to health services.

Some LGBTQI+ communities may have specific experiences that affect their health and wellbeing. Examples include:

- **transgender and gender-diverse people** – are less likely to access mainstream services because of transphobic attitudes, often have past experiences of misgendering and difficulties getting gender-affirming treatment
- **intersex people** – may have past negative experiences with health professionals, including prior surgery to make them “fit” society’s idea of what it is to be male or female, having had medically unnecessary surgery as a child without their consent, or dealing with health professionals’ lack of knowledge about intersex variations
- **young people** – may have higher rates of distress because of being bullied at school, rejected by family members, or still being in the process of coming out
- **older people** – would have likely grown up at a time when being homosexual was considered an illness or a crime and may have experienced discrimination, family rejection and social isolation
- **Aboriginal and Torres Strait Islander people** – brother boys or sister girls may face added discrimination from being both LGBTQI+ and Aboriginal or Torres Strait Islander (from the wider community, their own community, or both)
- **culturally and linguistically diverse people and refugees** – may face discrimination from within their community as well as the LGBTQI+ communities, leading to feelings of stigma and shame
- **people with disability** – may face discrimination from being both LGBTQI+ and a person with disability, which may lead to difficulties accessing services and having their sexual orientation, sexual needs or gender recognised
- **people living in regional or rural areas** – may be more socially isolated, less supported to come out, and have less access to LGBTQI+ specific services.

“I was incredibly worried about how we’d be treated as a queer couple... Turned out that we had no problems at all, but it was horrible that my brain thought of that first.” CHARLIE (QUEER, NON-BINARY)

Fear of discrimination

Some LGBTQI+ people have experienced discrimination because of their sexual orientation, gender or intersex variation, and fear being discriminated against during their cancer care.

Discrimination can take many forms, such as inappropriate comments, receiving a lesser standard of care, and excluding your partner/s from discussions or your hospital room. These types of behaviour can affect your physical and mental health and are against the law in Australia. For more information, see the *Dealing with discrimination* chapter.

Coming out to your cancer care team

At the time of the cancer diagnosis, you may or may not have come out as LGBTQI+, or you may be out to some of your friends, family and contacts but not others. Some people want to be out to their cancer care team, others feel it is not important, and some may not have a choice because information about their body is already in their medical records.

Choosing to come out to your cancer care team may make it easier for you to discuss your needs, preferences and values, and can help ensure you receive culturally safe care. It also means that your treatment team can recommend the most appropriate treatments for you, give you relevant information and connect you to LGBTQI+ support groups.

Whether you feel safe coming out to your cancer care team may depend on whether you're still questioning or exploring your identity, your past experiences of discrimination and prejudice, and whether you have been mistreated by other people after disclosing your sexual orientation, gender or intersex variation. It may also be influenced by how you felt when you came out to family and friends.

The reality of having cancer treatment is that you are asked to repeat your cancer experience multiple times with multiple doctors. You also need to decide whether to share your sexual orientation, gender or intersex variation with each health professional you meet. Coming out is a process, and it's okay to come out slowly and when you feel ready. This can be stressful and emotionally draining, and you may be worried about how your health professionals will react.

Benefits of coming out

- You don't have to hide who you are and can be yourself.
- You may be more satisfied with your cancer care and feel that it better meets your needs.
- Your partner/s (if you have them) are more likely to be recognised and included.
- It makes it easier to talk about how treatment affects sex and intimacy.
- Your treatment team can tailor information for you.
- You will be less likely to have your cancer overlooked.

Fears about coming out

- Fear of negative reactions and being made to feel unsafe.
- Worry about receiving discriminatory or a lesser standard of care.
- Anxiety about having to come out multiple times.
- Fear of being alienated from your family at a time of need.
- Concerns about potential breach of confidentiality.

When you may not have a choice

Sometimes it may be medically necessary to share information with your cancer care team, so they have the information they need to make a diagnosis or recommend treatment. This could include which reproductive organs you were born with, whether you have an intersex variation, or whether any sex characteristics have changed over your life.

People with an intersex variation may not have a choice about how much to reveal to their cancer care team if these details are listed on their medical records, and you may find this upsetting. However, you may want to share your preferred terms for body parts and discuss how your intersex variation will impact your cancer care (see pages 54–58).

You can work with your doctors and treatment team to ensure your information is shared and discussed with respect, and that you are not outed or discriminated against.

What if I'm not out?

You may not be out to all your family and friends, and don't want your cancer care team to share personal information with others. If you decide to come out to your cancer care team, they are legally required to keep your health information private and generally can't share it without your permission. If you are worried about being outed, it can be helpful to let your cancer care team know.

“I came out as gay just before I was diagnosed. I was still very uncomfortable with myself. And then I was diagnosed with cancer and that took precedence.” CARTER (GAY MAN, LEUKAEMIA)

How to come out to your health professionals

You deserve to be treated with respect by all the health professionals who look after you. If you find the thought of disclosing your sexual orientation, gender

Decide beforehand



Before your appointment, think about how much information you want to share and who you want to share it with. Prepare some notes so you don't forget anything.

Practise



You may feel more confident talking to your health professional if you practise what you want to say with your partner/s, family and friends.

Have someone with you



Consider having a support person, such as a partner, family member or close friend, with you to help with the discussion and to provide support. They can also help you debrief and provide assistance with making a complaint if you receive a negative reaction. If you don't feel safe, you can choose to leave the room.

Do it in writing



If you're not a confident speaker, write down what you want to say to your health professionals. You can also ask your GP to include information about you in their referral letter to other specialists, such as your sexual orientation, intersex variation, pronouns or preferred name.

or intersex variation stressful, some of the following tips and suggestions may be helpful to you.

Ask for privacy



If you're in a ward or open area, ask to speak in a quiet, private place where you won't be overheard.

Communicate your pronouns



Consider including your pronouns when you introduce yourself. You could say "My name is Parker Jones and I use they/them pronouns". If you are misgendered, you could provide a simple correction such as "Oh, I use they/ them pronouns, thanks." Wearing a pronoun badge is another way to remind people of your pronouns.

Introduce your partner/s



If you have a partner or partners, encourage them to come to your appointments. This lets your doctor know who's important to you. Before your first appointment, it's okay to phone or email your doctor to find out if they are LGBTQI+ friendly. You could say, "My wife will attend the appointment with me, we are both women, just so you know."

Communication aids



You can use the Genders, Bodies and Relationships Passport to make telling your health professionals about your gender, body and relationships easier. Visit lgbtiqhealth.org.au/passport to order a copy.



Seek support

Contact QLife, a national peer support and referral service for LGBTI people. Call 1800 184 527 or visit qlife.org.au.



Dealing with discrimination

Discrimination is when you are treated badly or less fairly because you have a particular attribute. Many people worry that they will face discrimination if they tell their health professionals they are LGBTQI+. While many health professionals are caring and supportive, discrimination in cancer care can happen. However, there are laws to protect LGBTQI+ people seeking health care. Knowing your rights may help reassure you that you are being treated fairly.

Is discrimination unlawful?

Under the Commonwealth *Sex Discrimination Act 1984*, it is against the law for health professionals, hospitals and treatment centres to discriminate against you because of your sexual orientation, gender or intersex status. It is also unlawful for them to discriminate against same-sex couples. Legislation in most states and territories also protects people from discrimination in certain areas of public life, including health care, because of their sexual orientation or gender.

Examples of unlawful discrimination in the health care setting include:

- refusing to provide you with care because you are LGBTQI+
- providing you with a lesser standard of care because of your sexual orientation, gender or sex characteristics
- making offensive comments, jokes or negative remarks about LGBTQI+ people
- not acknowledging your same-sex partner/s as next of kin (see pages 11–12)
- using incorrect names and pronouns on purpose.



How to deal with discrimination

- If you feel comfortable and safe doing so, raise the issue with the health care facility. All hospitals and health services should have a procedure for patients to provide feedback and complaints. Check with the cancer care coordinator, social worker or nursing staff.
- Make notes about the behaviour or incident. List dates and names of people who saw the behaviour. This will help you remember what happened so you can explain it later.
- Think about what you would like to happen to resolve the issue. A quick conversation may help to sort out any simple misunderstandings.
- If your complaint is about a specific person and you don't want to talk to them directly – or you have spoken to them and the issue remains unresolved – speak to the cancer care coordinator, nursing unit manager or social worker at the hospital or treatment centre about the complaint.
- Most complaints are resolved through mediation or conciliation. This is an informal way of agreeing on an outcome.
- If mediation or conciliation doesn't help, you may have the option to go to an administrative tribunal or to court for a legal judgment that must be followed.
- Contact the Australian Human Rights Commission (call 1300 656 419 or visit humanrights.gov.au) or the discrimination agency in your state or territory to lodge a complaint. Contact these organisations or seek legal advice to work out which organisation is best for your situation before you lodge a complaint.
- Talk to a lawyer for specific advice about your situation. Cancer Council 13 11 20 may be able to refer you to a lawyer for legal advice (which may be free if you cannot afford to pay).



The Australian Charter of Healthcare Rights describes the rights you can expect when using health services, including the right to receive health care in an environment that is inclusive, safe and respectful. For more information, visit safetyandquality.gov.au/your-rights.

Harassment

People may have different ideas about what is offensive or unacceptable behaviour. Just because the person did not mean to be offensive does not make it okay. You have the right to complain if you feel that you've been intimidated, bullied or harassed by health professionals, other hospital staff or other patients, or if you experience hurt, humiliation or distress because of their actions.

Other types of complaints

Health complaints organisations – If you are unhappy about the ethical or professional conduct of a health practitioner, you can contact the health complaints organisation in your state or territory. Serious cases may be referred to the Australian Health Practitioner Regulation Agency (AHPRA). For more information, visit www.ahpra.gov.au.

Medical negligence – This booklet does not cover breaches of duty of care by health providers. If you are thinking about making a medical negligence claim, seek independent legal advice.

▶ See our *Cancer Care and Your Rights* booklet.

Body image, gender and cancer

Cancer and its treatment can change the way you look. This can affect how you feel about yourself (body image), regardless of sexual orientation, gender and sex characteristics. Even if other people can't see the changes, they may still affect your body image.

This chapter discusses some common physical changes to appearance after treatment. These may also affect how you feel about sex and intimacy (see pages 33–41). The changes you experience will depend on the type of cancer and treatment you have. Some of these changes are permanent, but others may improve with time.

How you feel about changes to your body image will vary. You might find some are positive, and others might be negative. You may feel less attractive. This can affect your identity, self-confidence, self-esteem and body image, which may mean you socialise less or feel excluded from your community. In some cases, you may feel that your body now aligns more closely to your identity.

“Body wise, the most obvious thing that has changed is my hair. So I guess the way I present is a lot more obviously lesbian at the moment. And the way people would read me and my partner when we’re out is, yeah, that looks like a lesbian couple.” ELLEN (LESBIAN, CANCER OF THE UTERUS)

Removal of a body part

Surgery to treat some types of cancer may mean removing a part of the body that affects how you look. For some, the surgery affirms their gender. After surgery, you may choose to live with your new body shape, wear a prosthesis or have a reconstruction. Only you can decide what feels right for you.

Loss of a breast – Treatment for breast cancer may include breast conserving surgery (removing part of a breast) or a mastectomy (removing one or both breasts). Having a mastectomy is different from top surgery – see page 49 for more information.

After a mastectomy, you may choose to have a reconstruction or “go flat”. Some people who go flat, decide to have the area decorated with a tattoo. This can be to cover scars or to help people feel that they are in control of their body and how they express themselves.

What you decide may depend on whether the surgery affirms your gender, and whether the changes mean your body aligns with how you feel it should be. You may feel that the treatment team assumes that you will want a reconstruction after a mastectomy. Talk to the team about your goals for treatment so they can work out the best options for you.

► Visit bcna.org.au for more information on body image and gender identity.

Loss of the gynaecological organs – If the ovaries, uterus or cervix are removed, this can affect how you experience sexual intimacy.

Loss of a testicle – Some people who have had a testicle removed, may have less confidence and feel less sexually desirable. For cisgender men, the loss of a testicle may make them feel less masculine.

Some people adjust quickly to having one testicle, while others find that it takes some time. If you are self-conscious about how your scrotum looks, you may want to consider having an artificial testicle (called a prosthesis) inserted.

Loss of the prostate – During surgery, the tubes from the testicles are sealed and the prostate and seminal vesicles are removed. This means semen is no longer ejaculated during orgasm. The pleasure from rubbing or stimulating the prostate during anal sex will also be lost.

Shortening or loss of the penis – After treatment for prostate cancer, your penis may be a bit shorter when not erect. After treatment for cancer of the penis, the penis may be removed (penectomy). If the size of your penis is affected, you might avoid intimacy for fear of rejection. Your health care team can recommend a range of methods to change how the penis looks.

- ▶ Visit pcfa.org.au to download their booklet *Understanding Prostate cancer for LGBTIQ+ people*.

Weight changes

Some cancer treatments may cause you to lose weight. This may be because you lose your appetite, or you have taste changes or trouble swallowing. If you are taking medicines such as steroids or androgen deprivation therapy (ADT), these may cause you to put on weight.

Everyone responds differently to changes in weight. Your reaction may depend on your age, and how important your appearance is to you. For some, their changed body shape may feel more affirming, but others may feel less comfortable about their body after changes to their weight.

Bowel changes

Radiation therapy can irritate the lining of the bowel and rectum. Symptoms may include passing smaller, more frequent bowel movements (faeces, also called stools or poo), needing to get to the toilet more quickly, or feeling that you can't completely empty the bowel. These changes may mean that you avoid going out for fear of having an accident, or you avoid sexual activity (see page 34). Talk to your treatment team if you are finding it hard to cope with this side effect.

Loss of hair from the head and body

Hair loss or hair thinning is a common side effect of some cancer treatments, including chemotherapy and radiation therapy. If you experience hair loss, you may have a range of different emotions such as anger, anxiety and feeling low or depressed. Hair loss can make you feel self-conscious about your appearance and be a constant reminder that you have cancer.

For some LGBTQI+ people, head and body hair can be an important part of how they express their sexual orientation and gender. It can be a way of signalling that they have rejected gendered expectations of how they should look, or beards or long hair may help affirm their identity. Losing hair because of cancer treatment can challenge this expression of identity and self-image. For others, short hair after treatment may make them feel more visible as an LGBTQI+ person.

Everyone deals with hair loss differently. You might want to wear wigs, scarves and hats, or you might feel comfortable leaving your head bare. You may want to take control of the hair loss by shaving your head before treatment.

▶ See our *Hair Loss* fact sheet.

Gender-affirming hormone therapies

Some cancers depend on hormones to grow (e.g. oestrogen may help breast cancer to grow, testosterone may help prostate cancer to grow).

If you are diagnosed with a hormone-dependent cancer and are taking gender-affirming hormones, your

doctor may suggest adjusting your treatment (see page 52). You may find this difficult to do, particularly if how you look changes. This is known as gender dysphoria. If this makes you feel anxious or depressed, it may help to talk to your doctor or call QLife on 1800 184 527.

Other changes to your appearance

Scars – Surgery or radiation therapy can cause scarring. Scars usually fade over time and are harder to see. Sometimes people worry because a scar looks or feels red, tight and uncomfortable. This may make you feel self-conscious, even if others can't see it. Ask your doctor about creams that may help the scar heal and become lighter in colour. In some cases, you may choose to have surgery to make a scar less noticeable.

Skin changes – Itchy, red and dry skin can be a side effect of some targeted therapy, immunotherapy and hormone therapy drugs. Radiation therapy can also cause skin changes. These changes can make you feel self-conscious.

Lymphoedema – If the surgeon removes lymph nodes from your armpit, groin or pelvic area, the lymph fluid may no longer drain properly, and your arm or leg may swell. This is called lymphoedema. Although lymphoedema may be permanent, the pain it causes can usually be managed. Ask a lymphoedema practitioner whether wearing a compression garment would help.

► See our *Understanding Lymphoedema* fact sheet.

Stoma – Occasionally, surgery for bowel, anal, ovarian or bladder cancer means you need a temporary or permanent opening in the body (stoma). For a bowel stoma, a new opening in the abdomen allows bowel movements (faeces, also called stools or poo) to empty into a bag that sticks onto the skin of your abdomen. For a bladder stoma, a new opening collects and stores urine (pee or wee). Getting used to the stoma takes time. You may feel self-conscious about having a stoma, and worry that it can be seen under clothing, but it usually isn't noticeable. For information about sexual intimacy when you have a stoma, see page 35.

▶ See our booklets on bowel cancer and bladder cancer.



Ways to adjust to changes in appearance

- Keep in mind that body image is based on a mix of emotional and physical factors, not just on a body part or physical characteristic.
- Exercise regularly. It can help improve body image, quality of life, and reduce the risk of cancer coming back. Consider seeing an exercise professional for a tailored exercise program.
- Wear accessories and clothes that make you feel good or highlight your favourite features.
- Look at your “new” body in the mirror to get used to how it has changed.
- Talk to your GP or a psychologist if you have trouble adjusting to the changes to your body.
- Connect with people on social media who have similar experiences. They may have suggestions on how to adapt to your changing appearance.
- Ask your doctor about reconstructive surgery, prosthetic devices and/or cosmetic solutions. These are not for everyone but may help improve self-esteem and body image.

▶ See our *Living Well After Cancer* booklet.



Sexual intimacy and cancer

For many people, sexual intimacy is an important part of life. Cancer treatment can affect sexual activity and intimacy in several ways:

- your desire to have sex (your libido)
- your body's ability to respond to sexual stimulation
- how you feel about your body (body image)
- how you feel about sex and intimacy
- how you feel about your relationships.

The stress of a cancer diagnosis and treatment can affect your sex life too. Many people find changes to sexual activity and intimacy to be one of the most difficult aspects of life after cancer. While talking about these changes can be hard, the challenges of cancer can also strengthen a relationship, and lead to new ways to express intimacy.

Treatment side effects and sexual intimacy

Side effects will vary from person to person, and depend on the type of treatment and medicines you have. Some people have no side effects, while others have many.

Changes to sex drive or desire – Your libido might change because of tiredness, pain, anxiety, changes in hormone levels, and loss of confidence and self-esteem. For some people, libido may return to your usual levels after treatment ends, but for others, low libido may continue. Hormones can also change with age, and it's common for libido to decrease as you get older. Even if you feel like having sex, you might feel anxious about your partner/s seeing how your body has changed.

Pain during sex – Radiation therapy to the pelvic area or rectum may make sex painful. This usually improves after treatment ends.

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, uterus, vulva, vagina and penis. This may be temporary or permanent. Having bladder or bowel issues can be embarrassing and you may worry about having accidents or leaking during sexual activity. You can use a sex blanket, cover sheets or have sex in wet areas like a shower.

Weak pelvic floor muscles can affect bladder and bowel control. The hospital continence nurse or physiotherapist can suggest exercises to strengthen the pelvic floor muscles and manage urinary symptoms. Start these exercises before treatment and continue to do them regularly after treatment.

Leaking urine at orgasm – After surgery for prostate or vulvar cancer, you might leak a small amount of urine when having an orgasm. This is usually temporary but is sometimes ongoing. You may feel embarrassed and nervous at the thought of leaking urine during oral sex and/or masturbation. Reassure your partner/s that urine is sterile.

Changes to the anus – Radiation therapy to the abdomen or pelvic area may irritate the lining of the bowel and rectum. This can cause bowel problems, and the skin inside the anus may be more sensitive. If the anus area is sensitive after radiation therapy, take it slow and work up to full penetration. Fingering, rimming, using small dildos and picking positions where you control the speed and angle of penetration may help. Although sensitivity to the anal area may improve after a few months, some changes are permanent.

Sex with a stoma – Some types of surgery for bowel, anal, ovarian or bladder cancer create a stoma. This is an opening in the abdomen that allows faeces and urine to be collected in a small plastic bag. Sometimes a stoma is needed for only a short time, but sometimes it is permanent. Planning can help make sexual intimacy for people with a stoma satisfying and fulfilling. Consider wearing clothing like a slip or cummerbund to cover the stoma. You could secure the bag with tape to stop it moving. Talk to a stomal therapy nurse about products such as smaller pouches or a stoma cap. Do not use the stoma for sex.

Early menopause – Some cancer treatments can cause menopause symptoms or early menopause. These include surgery to remove both ovaries; hormone therapy to block oestrogen; and radiation therapy and chemotherapy, which can damage the ovaries. Menopause symptoms can include a dry vagina and mood changes, both of which can affect libido.

Safety concerns for partners

Your doctor may advise you to use barrier protection during specific sexual activities to reduce any risk to your partner from cancer treatment and to avoid pregnancy.

Chemotherapy – The drugs may be released into your body fluids. For penetration, use condoms or internal condoms. For oral sex, use condoms, internal condoms or dental dams (latex squares). Wear latex gloves if using hands for penetration. If you have anal sex,

use condoms. Clean sex toys after each use, and do not share between partners without using a new condom. Ask your doctor or nurse how long you need to use protection.

Internal radiation therapy (brachytherapy) – If you have radioactive seeds inserted to treat prostate cancer, you will usually be advised to avoid anal sex or use barrier protection (such as condoms) during treatment. Ask your doctor how long to wait before having sex.

Changes to the vagina – Cancer treatment may cause temporary or permanent changes to the vagina. Surgery may shorten the vagina, and pelvic radiation therapy can narrow the vagina, causing thinning of the walls and dryness. If you have a surgically created vagina (vaginoplasty), speak to your doctor about the effects of radiation therapy.

Penetration with fingers, a penis and/or sex toys such as dildos or other objects may be difficult and painful. A narrower vagina will also make cervical screening uncomfortable. Talk to your doctor about the options for keeping the vagina open. They may suggest using dilators in different sizes to dilate and extend the vagina. Using extra lubrication may make sexual intercourse more comfortable. Choose a water-based or silicone-based gel without perfumes or colouring.

Changes to the prostate – Pleasure experienced from rubbing or stimulating the prostate during sex may change with certain prostate cancer treatments. If you have radiation therapy, the prostate may feel less sensitive. You won't feel the same pleasure if the prostate is removed with surgery (radical prostatectomy). It may take time to adjust to this change and for you to become more aware of other pleasurable sensations.

Changes to the penis – Surgery for prostate or penile cancer may shorten or shrink the penis. After prostate cancer surgery, the difference is often small, usually about 1 cm. Changes in size may happen because of scar tissue or the nerves not working properly.

Erection problems – After surgery for prostate cancer or bowel cancer, getting and keeping a firm erection can be difficult. This is known as erectile dysfunction or impotence. How long the problem lasts will depend on your age, how easily you got an erection before surgery and

how much the erectile nerves were damaged. Having radiation therapy or taking androgen deprivation therapy can also cause erection problems.

You don't need an erect penis to have an orgasm. However, firmer erections are needed for penetrative sex. Erection problems can make having penetrative sex more difficult or painful, and you may find this makes you feel anxious and frustrated. Doing pelvic floor exercises can help improve erections. Other options include using erection aids such as a vacuum pump, constriction ring around the base of your penis, or medicines. Ask your doctor for more details about these methods.

Other ways to experience pleasure include masturbation or oral sex, but you may be worried about how your sexual partner/s may feel. Open and honest communication about what has changed and non-sexual touching can help maintain intimacy in a relationship.

Changes in ejaculation – After some types of surgery and radiation therapy (e.g. for prostate cancer), you won't be able to ejaculate semen. This is known as dry orgasm. This is because semen is no longer produced. If ejaculating semen was an important part of enjoying sex for you or your partner/s, you might want to discuss this change with them.

“As far as I can see, gay men pick each other up on Grindr. And that is a much more explicit sexual thing – come over and I'll perform or you perform or whatever. And I'm not up for that. I don't take the risk that things won't work properly.” TROY (GAY MAN, PROSTATE CANCER)

Adapting to changes in your sex life

Changes to how you enjoy sexual intimacy and activity can be challenging and upsetting. Give yourself time to adjust. There are several ways to adapt how you

Talk about what has changed



Share any concerns about having sex or being intimate with your partner/s. Tell them when you are ready to have sex, what still works for you, what doesn't and if they should do anything differently.

Try other forms of intimacy



Show affection by cuddling, holding hands, lying together naked, kissing and massaging. Talk about what has changed to avoid misunderstandings and take the pressure off going further.

Explore different ways to have sex



If the way you used to have sex has changed, try different sexual positions; explore different erogenous zones; manual sex, including fingering and fisting; mutual masturbation; oral sex; genital rubbing; personal lubricants (lube); vibrators and other sex toys; erotic images and stories; sexual fantasies and kink.

Plan ahead



Using lubricants (lube) and erection devices, taking medicines, and managing incontinence or stomas may all mean you have to plan when to have sex. Some people say they miss spontaneity, others find that scheduling sexual activity gives them something to look forward to.

have sex during or after cancer treatment. You might find some of the following tips useful. See our *Sexuality, Intimacy and Cancer* booklet.

Focus on other aspects of your relationship



Many people in relationships do not see sex as important. How you feel about sex may also change as you get older. Spend time together doing things you both enjoy that also bring you closer. That way, sex isn't the only way that you show your affection and share intimacy.

Use relaxation and meditation techniques



Feeling relaxed can help with sexual pleasure. Use free apps and podcasts to guide you through learning relaxation and meditation techniques. Many treatment centres run meditation programs.

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

Explore what has changed on your own



Touch and masturbation can help you to understand any changes in how you feel in a way that you have complete control over. You can figure out what feels good to you, or what feels sore or numb, without feeling self-conscious or pressure to “perform” or to keep going if you don't want to. Once you feel comfortable exploring your body, you can show your partner/s what feels good and works best.

Seek assistance



Ask your health care team how to manage any sexual changes. Your doctor can also refer you to a sexual health physician, sex therapist or psychosexual counsellor. See page 69 for more information.

Communicating with your partner/s

Coping with treatment and recovery may affect your relationship with sexual partners. Your established roles may change, they may worry about hurting you, or you might feel too tired for intimacy.

Research suggests that communicating during treatment can help partners work through any issues. If you find that the changes after cancer treatment are getting in the way of a fulfilling sexual life, ask your GP or cancer specialists for a referral to a counsellor, sexual health physician or sex therapist.

Sexual activity and LGBTQI+ young people

Adolescence and the young adult years are a time for exploring your sexuality and identity, including your sexual orientation and gender. This process can be more complex if you are diagnosed with cancer. If you've recently started exploring your identity, needing to have treatment for cancer can interrupt this.

Feeling isolated – If you already feel different or isolated from people your own age because of your sexual orientation, gender or intersex variation, cancer can make you feel even more lonely.

Worrying about disclosure – Getting diagnosed and treated for cancer means accessing many health services. It can be challenging to talk about your sexual orientation, gender or intersex variation with others when you are still working it out yourself or have only recently come out. Some young people hide their identity from health professionals, because they fear being judged, discriminated against or outed to family.

Get in touch with Canteen. This organisation offers counselling in person, via phone, email or direct message (DM). Canteen also runs

online forums and camps. Call 1800 226 833 or visit canteen.org.au. If you're feeling anxious or depressed, call QLife on 1800 184 527.

Sexual activity and single people

If you're single, you may feel nervous about hook-ups or starting a new relationship during or after treatment. You may wonder if you have to tell a new person about your cancer diagnosis and when to do this. This could depend on whether the relationship is casual, or you see it becoming more long term.

It may help to take new relationships slowly and share personal information when you feel you can trust the person. You can discuss how to adapt your sexual activity, try more activities without penetration, or change the length and intensity of your sexual encounters. You can also talk to a psychosexual or relationship therapist for more suggestions.

You might decide that you want to focus on your health and wellbeing or that you don't have the energy for hook-ups or a new relationship.



Tips for hooking up

- Set boundaries via messages before meeting.
- Consider adding something about your cancer journey on your dating profile.
- Share details of your diagnosis and side effects when you feel ready. You don't have to reveal everything in one go. You can disclose the details over several conversations. It can be in person or via text.
- Practise what you want to say and how you say it, so it feels more natural.
- Talk to a psychosexual or relationship therapist for strategies and support.



Fertility after cancer

Many LGBTQI+ people hope to start a family. The path to becoming a parent is different for everyone. Having biological children is one way of starting a family, and one that is possible for some LGBTQI+ people. But it can be made difficult due to cancer treatments affecting your fertility.

Before starting treatment, it's important to discuss how cancer treatments may affect your ability to conceive a child or maintain a pregnancy (fertility) and your options for fertility preservation. You can still consider your fertility later, but there may not be as many options available after treatment.

Your doctor may not discuss whether you want children in the future if they make assumptions based on your sexual orientation, gender or intersex variation. If fertility matters to you, let your health professional know.

How cancer treatments affect fertility

Cancer and its treatment may affect your fertility. This will depend on the type of cancer, whether you've had surgery, chemotherapy or radiation therapy, and your age.

Infertility caused by treatment can be temporary – difficulty conceiving may happen only during treatment or for months or years after treatment. Sometimes it is permanent. Treatments can also cause early menopause. You will be advised to avoid conceiving during cancer treatment and for a period of time afterwards.

Ways to preserve fertility

There are different ways to preserve fertility before and after treatment. Keep in mind that these methods don't work all of the time. For more information about options before and after treatment, see our *Fertility and Cancer* booklet.

Options before treatment

Ask your cancer care team for details about the cost of having fertility preservation and storing eggs, embryos or sperm. Options include:

- freezing or banking sperm
- freezing eggs or embryos
- freezing ovarian tissue
- surgically moving one or both ovaries out of the field of radiation to preserve their function (oophoropexy)
- preserving the uterus, fallopian tubes and ovaries during surgery
- for early cervical cancer, surgically removing part or all of the cervix, the upper part of the vagina and the lymph nodes in the pelvis, but leaving the uterus, fallopian tubes and ovaries in place (trachelectomy)
- suppressing the ovaries with a long-acting hormone called GnRH analogue treatment before chemotherapy to cause a temporary menopause and protect eggs from damage
- shielding the testicles during radiation therapy to protect them.

Options after treatment

This will depend on how cancer treatment has affected your fertility. Ways to become a parent after treatment include:

- using donor eggs from your partner, another known donor or from an overseas donor
- using donor sperm from your partner, a friend or family member or overseas donor
- asking someone (a surrogate) to carry your embryo if you do not have a uterus or it is medically too risky for you to carry a pregnancy
- adopting a child
- fostering a child for emergency, respite, short-term or long-term care – in Australia there are more opportunities to foster than there are to adopt.

Checking fertility after treatment

After treatment, you may want to do some tests to see how your fertility has been affected. These may include: blood tests to measure different hormones; sperm count; or ultrasound to check the health of reproductive organs. Some tests, such as certain types of ultrasound, may be challenging for some LGBTQI+ people. The results help your fertility specialist or reproductive endocrinologist recommend the best options for having a child after cancer treatment.

Pregnancy after cancer treatment

You might be advised that you need to wait several years after treatment ends before trying to get pregnant. There are many ways to approach conceiving a child, either on your own, or with a partner.

If you or your partner can become pregnant – Options include:

- Your partner could have their eggs fertilised with donor sperm through IVF and then carry the pregnancy.
- If your eggs were collected before treatment or are undamaged after treatment but you've had your uterus removed, you could consider reciprocal IVF. This means you go through the IVF cycle and once the embryos mature, they are transferred to your partner to carry the pregnancy.
- If your eggs have been damaged, but you have your uterus and your partner has ovaries, your partner's eggs could be fertilised with donor sperm and then you carry the pregnancy.
- If neither of you can provide eggs, you could use donated eggs.

If you and your partner produce sperm – You will need an egg donor and a surrogate to start a family. If your sperm has been damaged, your partner may be able to provide sperm. If neither of you can provide sperm, you could use donated sperm.

If you are single – You could consider using eggs and/or sperm donated by another person or from overseas.

Emotional impact of infertility

How people respond to infertility varies. Common reactions include shock at how cancer or its treatment has affected fertility; grief from the loss of future plans; anger or depression from disruption of life plans, and loss of control over life direction.

These feelings may be intensified by the physical and emotional process of having infertility treatment and by not knowing if it will work. People who didn't get a chance to think about their fertility until treatment was over say the emotions can be especially strong. It may also help to consider other ways of becoming a parent, such as adoption or fostering, or you may decide to stop trying to have a child.

Infertility and relationships

Cancer and infertility can cause tension within a relationship. How your relationship is affected may depend on how long you have been together, expectations about becoming parents, the strength of your relationship before cancer and infertility, and how well you communicate.

Changes to your fertility may mean renegotiating who will provide eggs or sperm or carry the pregnancy. If your partner is unwilling to be the biological parent, you might feel like you've missed the opportunity to have a family. Seeing a fertility counsellor can help you talk about these issues and suggest ways to cope.

If you're starting a new relationship, you may want to share your cancer diagnosis and impact on fertility when you feel you can trust the person.



Trans and/or gender-diverse people

This chapter discusses some of the ways being transgender (trans) and/or gender diverse may affect cancer treatment. Making decisions about treatment can be difficult when cancer develops in your chest or in a reproductive organ.

Having cancer treatment and managing side effects often means doctors will refer to the sex you were assigned at birth. You can ask your doctor to talk about you as your affirmed gender.

If you find the information in this chapter distressing, read the parts you are comfortable with now and come back to others when you feel ready. You can also contact QLife on 1800 184 527 (3pm–midnight) for support.

Cancer care as a trans and/or gender-diverse person

Your cancer care team should offer you care, support and information that meets your needs, respects who you are, and helps you to make informed decisions about treatment. They should treat you as an individual and work with you in a way that respects your privacy and dignity. But research shows that because health professionals have less confidence and experience in treating trans people, they may struggle to provide inclusive and gender-affirming care.

Discrimination and past negative experiences (see page 4) are common reasons why a cancer diagnosis may be challenging for trans and/or gender-diverse people.

Challenges you might face

Lack of experience – It may be harder to find cancer specialists with an understanding of the ways in which trans health needs affect cancer care. It can be difficult dealing with health professionals who think of sex as binary and you may fear being misgendered.

Misgendering – Health professionals may incorrectly assume your gender or that of your partner and use the wrong words or pronouns when referring to you. You might find this misgendering upsetting and it could undermine your trust and confidence.

Outdated forms – Many medical forms do not include options to record your gender, pronouns and sexual orientation. It can also get complicated if the gender or name you use on the form doesn't match the details on other official documents, such as your Medicare card.

Using gender-affirming hormones for a long time – Taking oestrogen for a long time may increase the risk of breast cancer. At this stage, it isn't clear if taking testosterone for a long time increases cancer risk.

Services that are gendered – Some cancers are screened and treated in a cisgender way (e.g. ovarian cancer in a women's hospital), which can feel isolating if you are trans or gender diverse.

“At the time of my diagnosis I was still passing as female and I was able to ‘fit in’ in the necessary environments like gynae offices. The psychological impact of having gynaecological parts involved was not lost on me.” JAX (TRANS MAN, OVARIAN CANCER)



Ways to manage challenges

- See a health professional who is affirming of your gender. To find a suitable doctor, use word of mouth or search transhub.org.au.
- Look for services that are trans friendly. See page 13.
- Tell your cancer care team about your relevant anatomy, the sex you were assigned at birth, and any hormone therapy you're taking. This can help the team recommend treatments and give you information that is right for you.
- Ask the receptionist to update your record with your name and pronouns, or consider wearing a pronoun badge or pin.
- Practise what you want to say to your doctor before an appointment to help the words come out more easily. Or read from a pre-prepared letter. Avoiding eye contact may make it easier.
- Let your health professionals know what language you are comfortable with for body parts.
- Bring someone to your appointments for support. They can speak for you if you don't know what to say, get tongue-tied or freeze in a challenging situation.
- Use the Genders, Bodies and Relationships Passport to make telling your health professionals about your gender, body and relationships easier. Visit lgbtiqhealth.org.au/passport for more information and to order a copy.
- Explain what is important to you. This could include concerns about whether you will be able to continue gender-affirming treatment.
- Visit canwe.org.au to find screening programs that are right for you.
- Consider making a complaint if you think you've been treated inappropriately. See also *Dealing with discrimination*, pages 24–26.

How cancer affects trans and gender-diverse people

Cancer can affect anybody, but there may be additional distress involved for trans people who have cancer in body parts that their doctors may not expect due to their gender, e.g. trans men with cervical cancer, trans women with prostate cancer, or non-binary people with any form of cancer.

It is important to screen for the parts of your body that you have. If you have had surgery to remove certain body parts (e.g. a mastectomy/top surgery, or reproductive organ/s), it can be helpful to talk with your surgeon and health care team about what (if any) cancer risk still remains after that surgery.

Breast cancer – Everyone has breast tissue in the breast and chest area, which means they could get breast cancer. But risks can vary:

- Trans and gender-diverse people who develop breasts at puberty have a similar level of risk to cisgender women.
- Trans women and gender-diverse people who have breasts from taking gender-affirming hormones have a similar level of risk to cisgender women.
- Trans men and other people who have had gender-affirming top surgery have a lower risk of developing breast cancer than cisgender women, but may still need to screen for breast cancer in the future.



Having a mastectomy for cancer is different from gender-affirming top surgery. A mastectomy removes all the breast tissue from half or all of the chest area and often the nipple. Top surgery usually keeps some breast tissue that can be formed into a masculine chest and often the nipple is retained. You may have had this procedure before you were diagnosed with cancer.

Prostate cancer – The prostate is not removed during genital reconfiguration (also known as sexual reassignment surgery or SRS). This means all trans and gender-diverse people who were born with a prostate can get prostate cancer. It is common for the prostate to grow larger with age. You may be at higher risk of prostate cancer if you have a family history of prostate cancer, or if you started hormone therapy for gender affirmation later in life and already had some cancer in your prostate.

Taking feminising hormones (such as oestrogen, or testosterone blockers) or having your testicles removed, reduces your risk of prostate cancer by lowering the levels of testosterone. Although the risk of prostate cancer is likely to be low, keep in mind the following:

- if your doctor does not know your trans status, they may not ask about any potential prostate symptoms
- your PSA blood test results may look different if you are taking hormones like oestrogen
- you may not have any prostate cancer symptoms, or symptoms such as urinary problems may be mistaken for symptoms related to gender-affirming surgery.

Other cancers of the reproductive organs – There are a range of cancers that affect reproductive organs, including cancer of the cervix, ovaries, testicles or penis. If you have any symptoms including pain, discomfort, or a change in feeling or function of these body parts, it is important to see a trusted doctor about them.



It can help to share how you're feeling about your diagnosis with a counsellor or psychologist. For ways to find support, see pages 69–72.

“Surgery for cancer alleviated me of some of the parts that were at the core of my gender dysphoria symptoms. I felt more whole than I had in my entire life.” JAX (TRANS MAN, OVARIAN CANCER)

Cancer treatment and gender affirmation

Some cancer treatments can have an effect on your identity. Talk to your cancer care team about what is important to you so this can be considered when working out your treatment options.

Surgery

Surgery to treat cancer may result in physical changes that make you feel uncomfortable or distressed about your body (dysphoria). Or surgery can affirm your gender and/or ease existing feelings of gender dysphoria. It's okay to not be sure how you're feeling or how you will feel.

If you need to stay in hospital, ask what ward you will stay on. You may be able to stay in a private room or mixed-gender ward. It can feel isolating to receive treatment in settings that do not reflect your gender.

Radiation therapy

If you have had genital reconfiguration, including surgery to make a penis or vagina, radiation therapy to the pelvic area may affect these organs.

If you have had surgery to make a penis – Pelvic radiation therapy can usually be given in a way that avoids this area. If you also still have a vagina (sometimes described by trans people as front hole), radiation therapy may make this area dry, narrow or cause bleeding. Your

treatment team may suggest using dilators regularly after treatment to help keep your vagina/front hole open. While dilators can be helpful for continuing to have cervical screening or sex, it's your choice whether or not to use them.

If you have had surgery to make a vagina – Pelvic radiation therapy may narrow the vagina or make the skin more fragile and sensitive. Keeping the vagina open and supple will make penetrative sex more comfortable, but it is also important for having medical examinations in the future or screening tests. You may be offered dilators to prevent scarring and shortening of the vagina. Some people find using a dilator upsetting. Talk to your doctor about your treatment goals, so they can understand what you'd like and how you feel.

If you have had other genital surgery – Other genital surgeries, including zero-depth vaginoplasty (to create a vulva) and metoidioplasty (to create a penis from the clitoris), may also be affected by radiation therapy. Talk to your surgeon and treatment team about what to expect and how you can look after yourself.

Using gender-affirming hormones during treatment

If you are taking gender-affirming hormones, you may be able to continue taking them during cancer treatment. This will depend on the type of cancer and treatment you had.

Talk to your team about the possible risks and benefits before you make

any decisions about taking a break, stopping or reducing your gender-affirming hormone treatment.

Your reasons for taking the hormones are also important and you may feel the benefits of continuing to take them outweigh the risks for you.



Cancer treatment can damage ovaries, testicles or other organs and affect your ability to conceive. See pages 42–45 for more information, and read our *Fertility and Cancer* booklet.

Impact of cancer treatment on body image

Some treatments for cancer may change how you look or affect a part of your body that aligns with your gender. For example, hair loss or a change in your body shape may be upsetting if your appearance is an important part of your identity. These changes may affect your body image and sense of self, and can be difficult to cope with.

You may also feel relieved if the changes affirm your gender. For example, surgery to treat cancer may remove a body part that you would prefer not to have. Or you may feel distressed if the changes threaten how comfortable you are in your body. How you react will depend on the type of cancer and treatment you have. See the *Body image, gender and cancer* chapter, pages 27–32, for more information.



Intersex people and cancer

This chapter discusses some of the ways having an intersex variation might affect treatment for cancer. There are at least 40 known variations of sex characteristics and it is estimated that they occur in about 2% of births.

Common variations include complete androgen insensitivity syndrome, 46,XY complete gonadal dysgenesis (Swyer syndrome) and 47,XXY (Klinefelter syndrome).

Cancer care as an intersex person

The cancer care team should offer you care and information that meets your needs, respects who you are, and supports you to make informed decisions about treatment. They should treat you as an individual and work with you in a way that respects your privacy and dignity. As an intersex person, you may have some added challenges. For example:

- it may be harder to find cancer specialists with an understanding of any health issues you have related to your intersex variation
- clinical practice guidelines that set out recommended cancer treatment pathways may not cover your situation, which can make it harder for you to make informed decisions
- you may avoid cancer screening because of the lifelong impact of inappropriate treatment to manage cancer risk
- surgery for cancer may be a reminder of surgery imposed on you as a child, which may be distressing and traumatising
- you may feel vulnerable because of your experiences of harassment, violence, stigma, exclusion and discrimination (minority stress).

Working in partnership with your cancer specialists to make decisions about your treatment and ongoing care may help you deal with these challenges. Research shows that many health professionals lack confidence and knowledge in treating intersex people. If you have a GP or other specialist looking after your ongoing medical care, they can provide your cancer specialists with any information that is relevant to your cancer care. This may include details about your intersex variation, the sex assigned to you at birth, your gender, your anatomy and any hormone therapy you take.

If you don't have a GP or other specialist you trust, think about what you want to say and how much you want to share with your cancer specialists. Take someone with you to your appointments to support you with this conversation. To get the correct cancer diagnosis and treatment, your doctor needs to understand your medical history, which may be confronting. See also *Dealing with discrimination*, pages 24–26.

“I do think an emphasis on intersex care is vital and long overdue in the health service as we are so overlooked as a community.” ALEX (PANSEXUAL, NON-BINARY,

INTERSEX, SKIN CANCER)

Challenges you might face

Having had prior surgery without your consent – Many intersex people had surgery as a child to assign a sex, to make their body align with gendered norms for male and female bodies, or to reduce the risk of cancer (see next page). This surgery may have changed the appearance or removed parts of the genitals and reproductive organs. It may have been done before you had the chance to decide, or your parents may not

have received enough information about the impact of the surgery to be able to give informed consent. Some people reject the assigned sex when they are old enough to decide their gender, and sometimes the surgery may not have been medically necessary. Both of these things can add to feelings of distress about having had prior surgery.

Feelings of distrust – You may have lost trust in family and health professionals who made decisions for you during childhood without your consent, particularly if you didn't find out about previous surgeries or medical interventions until you were an adult. Being told that doctors need to “fix” your body can make you feel ashamed and stigmatised. Some intersex people distrust the medical profession because of being made to feel like a research subject for doctors to learn from, being photographed or being asked insensitive questions about their genitals and internal organs.

Increased cancer risk – Some syndromes that cause intersex variations increase the risk of cancer. For example, males with 47,XXY (Klinefelter syndrome) have an increased risk of developing non-Hodgkin lymphoma and breast cancer.

The risk of gonadal cancer (cancer in the tissue that becomes testicles and ovaries) is also higher in people with some intersex variations such as 46,XY complete gonadal dysgenesis (Swyer syndrome). Surgery to remove the gonads may reduce cancer risk, however, this surgery has often been done on people with very low cancer risk. For some, ongoing monitoring can be a better way of managing this cancer risk. Talk to your doctors about the cancer risk for your variation.

Cancer screening – Talk to your doctors about suitable screening tests for you (see page 5). Depending on your variation, the sex assigned

at birth or any medical interventions you've had, you may not receive appropriate screening reminders for breast or cervical cancer, or you may receive notifications that you don't need. If you find the idea of screening tests difficult, talk to your GP or nurse. Ask them to explain what will happen. For some screening tests you may be able to collect the sample yourself, either at home (bowel cancer screening) or at the doctor's office (cervical cancer screening).

Taking hormones – You may have been prescribed hormones to supply the body with the sex hormones that it is not able to produce naturally or to bring on sexual development at puberty. If you've had surgery to remove the gonads, you may need lifelong hormone replacement therapy. This can be confronting if you did not give your consent for the surgery. You may also be on hormone therapy to affirm your gender if the sex assigned at birth does not match your gender as an adult.

Some cancers grow in response to hormones. Depending on the type of cancer and treatment you have, you may not be able to keep taking hormones prescribed for your intersex variation. It is important to discuss this with your cancer specialists, so you can make informed decisions about your future treatment.

Terms used – Health professionals can use a wide range of terms to describe intersex variations, including differences or disorders of sex development. You may find some terms offensive or distressing. Let your cancer care team know the terms you would like them to use.

Ongoing side effects – Previous surgery may have led to scarring, infertility, incontinence or loss of sexual function, which can all cause anxiety and mental distress. You may have had further surgeries as an adult to deal with some of these issues.

Gendered treatment – Some cancers are diagnosed and treated in a gendered way. This may make you feel excluded or stigmatised for not matching other people’s ideas of what it is to be a man or woman. Outdated forms may not include options to record intersex variations. Being made to feel different can lead to distress when you are talking with health professionals about cancer.

Body image – Surgery to treat cancer may remove a body part. You may be accepting of the change or you may be upset because you have lost a part that is important to your sense of self. You can talk about how you’re feeling with your treatment team before surgery. If you have previously had parts of your body removed without your consent, having to lose another body part may trigger feelings of distress. For more information, see the *Body image, gender and cancer* chapter on page 27.

Fertility – Some intersex people are fertile and others are not. It depends on the type of intersex variation as well as any surgery they may have had during childhood to remove testicles or ovaries. Given that many decisions that can affect future fertility are made before adulthood, and often without the consent of the person, it’s natural to feel grief and loss.

Some cancer treatments can also cause issues with fertility. People whose fertility is also affected by their intersex variation, say the emotions can be especially strong. It’s best to talk to a fertility specialist before treatment starts for information specific to you.



Getting support can help reduce feelings of distress. Talking to intersex-aware psychologists, counsellors, psychiatrists or other health professionals may be helpful. For more ways to find support, see pages 69–72.

LGBTQI+ people with advanced cancer

Advanced cancer is cancer that has spread from the original site or come back. Although medical treatments may not be able to cure advanced cancer, they may be able to slow its growth or spread, often for months or for years.

- ▶ See our *Living with Advanced Cancer* booklet and listen to *The Thing About Advanced Cancer* podcast.

Palliative care

Palliative care is person-centred care that helps people with a progressive, life-limiting illness to live as comfortably as possible. The main goal is to maintain your quality of life by dealing with your physical, emotional, cultural, social and spiritual needs. Palliative care also supports families and carers, including with bereavement care.

Depending on what services are available where you live, you can have palliative care at home, at a residential aged care facility, or in a hospital or specialist palliative care unit.

- ▶ See our *Understanding Palliative Care* booklet.

Barriers to inclusive palliative care

After experiencing a lifetime of discrimination and stigma, many LGBTQI+ people worry about receiving palliative and end-of-life care that is safe and meets their needs. Your concerns about receiving inclusive palliative care may also be influenced by any unpleasant experiences and negative attitudes you've had when friends had palliative care during the HIV/AIDS epidemic.

Reasons why LGBTQI+ people may avoid or delay accessing palliative care services include:

- a general distrust of health care providers based on past experiences of discrimination
- health care providers assuming that everyone is heterosexual, binary or cisgender, which can make it harder for LGBTQI+ people to have their care needs identified and met
- fear of negative attitudes, being harassed or having to hide their identity
- fear that health professionals will make assumptions about their gender, body or sexual orientation or not affirm their gender
- feeling afraid of being judged
- concerns about their physical safety
- concerns about not receiving respectful personal care
- worry about their partner/s or family of choice being excluded
- social isolation and lack of access to palliative care services
- lack of support with advance care planning (see pages 62–64)
- fears about facing end of life.

Other aspects of identity, such as age, race, culture, disability, and where you live, can influence how you feel about palliative care.

Respectful, inclusive care

All LGBTQI+ people have the right to palliative care that is safe, respectful and inclusive. It is unlawful for palliative care services to discriminate against LGBTQI+ people (see the *Dealing with discrimination* chapter, pages 24–26).

Some LGBTQI+ people who use palliative care services disclose their sexual orientation, gender and intersex variation, while others don't. It is your decision how much you choose to reveal, but letting your

palliative care providers know can help them best meet your needs. Hiding your identity can create another level of stress if you are afraid of being outed.

When looking for palliative care providers, consider asking how they make people feel safe, included and respected. This may provide an opportunity for you to raise any specific care needs relating to your sexual orientation, gender or intersex variation.

For ways to identify LGBTQI+ friendly services, see page 13.

Recognising family

Palliative care recognises the importance of involving partners, family and carers in decisions about care. The palliative care team will also provide family and friends with emotional support and referrals to counselling and grief support.

Some LGBTQI+ people are estranged from their family of origin and surround themselves with a chosen family. Other people are not out to their family or their family is hostile to their identity. Sometimes, conflicts can arise between the family of origin and the chosen family.

To ensure that the people you want to make decisions on your behalf are recognised by the palliative care service, you need to legally appoint one or more substitute decision-makers (see page 63).

Intimacy and palliative care

Many people say that sexual activity 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 at any stage.

If you have a partner or partners, try to spend intimate time together, rather than as “patient” and “carer”. If you are in residential palliative care, ask your treatment team if it’s possible to use a double bed so you can have some private time. Intimacy can provide comfort and maintain connection during this time.

Even if sexual intimacy is no longer possible or desired, you may enjoy physical closeness through cuddling, touching, massage or simply lying beside each other.

Advance care planning

When diagnosed with a life-limiting illness, it can be a good idea to plan for your future health care. Discussing your preferences with your family, friends and treatment team helps ensure that your wishes are respected if you lose the ability (capacity) to make your own decisions.

Everyone has their own individual preferences, and these will often change over time. Making your wishes clear can help give you peace of mind, protect your rights and ensure that the people you want involved in your care are included.

The following are steps to take as part of advance care planning:

Prepare an advance care directive – You can write down your goals and instructions for your future medical care in this document. It also provides a record of your values and treatment preferences. Doctors, family, carers and substitute decision-makers must follow this record if you become unable to communicate or make decisions. Depending on which state or territory you live in, it may be called an advance care directive, health direction or advance personal plan.

Appoint a substitute decision-maker – You can legally appoint one or more people to make treatment decisions for you if you are not capable of consenting yourself. A substitute decision-maker should be someone you trust, and who understands your values and preferences for care. They do not have to be your next of kin or a carer. Depending on where you live, they may be known as an enduring guardian, enduring power of attorney or medical treatment decision maker.

Appoint an enduring power of attorney – If you are unable to look after your own financial and legal affairs, you can legally give one or more people the power to make financial or legal decisions for you.

Make a will – A will is a legal document that sets out what you want to happen to your assets after you die. These assets are called your estate and may include your house, land, car, bank accounts, jewellery, clothes, household goods or investments. A will can also record your wishes regarding guardianship plans for any children you have.

A will needs to be prepared and written in the right way to be legally valid. It is best to ask a lawyer to help you or contact the Public Trustee in your state or territory. If you die without a will, you are said to die intestate. Your assets are distributed to family members according to a formula provided by the law. Although any will can be challenged in court, having a valid will usually means your assets will go to the people of your choice and avoids extra expenses.



Each state and territory has different laws about advance care planning. For specific information and advice, call Cancer Council 13 11 20. We may be able to refer you to a lawyer. You can also call Advance Care Planning Australia on 1300 208 582 or visit advancecareplanning.org.au.

Default decision-maker

If you lose the capacity to give consent for medical treatment and you haven't appointed a substitute decision-maker, consent may be given by a default substitute decision-maker. Depending on where you live, they may be known as the person responsible, default substitute decision-maker, available consentor, statutory health attorney or medical treatment decision-maker.

The law sets out who should make decisions on your behalf. They are usually approached in the following order:

- guardian – either an enduring guardian you appointed or a guardian appointed by a court or tribunal
- spouse or partner – the most recent spouse, including a de facto partner, with whom you have a close and continuing relationship
- unpaid carer – someone who provides ongoing care
- relative or friend – someone who has a close personal relationship and an interest in your welfare.

For more information on palliative care for LGBTIQ+ people, visit lgbtiqhealth.org.au/palliative_care.

Communicating openly

It can help to have the difficult conversations with your partner/s and family (chosen or otherwise) early, so that you are not rushed into decision-making. You may want to choose what you would like for your funeral, and take an active role in how you will be remembered. It can be easier for both you and your intimate partner/s to have certainty about this early so you can focus your energy on having treatment or feeling your best. It may not necessarily be a comfortable conversation, but it can be proactive, honest and deeply important for those involved.

Life after treatment

For most people, the cancer experience doesn't end on the last day of treatment. Life after cancer treatment can present its own challenges. You may have mixed feelings when treatment ends, and worry that every ache and pain means the cancer is coming back.

It is important to allow yourself time to adjust to the physical and emotional changes, and establish a new daily routine at your own pace. Your family and friends may also need time to adjust.

Finding a new normal

When treatment ends, you may see the diagnosis as an opportunity to make changes to your life. This process is commonly called finding a new normal. This shift is often gradual; even positive change can take time. You may:

- change the way you talk about yourself
- have a different perspective on life and seek out new experiences
- feel motivated to set up a support group for members of your community
- want to be more open about your sexual orientation and gender
- feel confronted by changes to your body
- place more value on spending time with family and friends and choose to focus on the more meaningful relationships in your life
- reconsider your career goals and work values.

It may help to share how you're feeling with your family and friends, your doctor, a psychologist or counsellor.

- ▶ See our *Living Well After Cancer* booklet.

Follow-up care

After treatment is finished, you will have regular appointments with your cancer specialists, cancer nurse or GP to monitor your health, manage any long-term side effects from treatment, and check that the cancer hasn't come back or spread.

Many cancer survivors say they feel worried before routine check-ups. Check-ups may feel easier once you've been to a few and things are going well. In the meantime, finding ways to cope with your anxiety before check-ups may help. Learning mindfulness and meditation skills, or practising deep breathing, can help you manage stress and anxiety.

► Listen to our *Finding Calm During Cancer* podcast.

Some treatment side effects can have a long-term impact and it may take time to adjust. Your treatment team should identify any emotional and physical needs you have for follow-up care and work with you to develop a plan to manage them. Your GP or specialist can refer you to a range of allied health professionals to help you manage some of the side effects of treatment and improve your quality of life. For example, you may see a psychologist to help you manage anxiety, a physiotherapist to help regain movement, or a sexual therapist for help dealing with the impact of sexual changes.

Having to disclose personal details again and establish a relationship of trust with new health professionals can be stressful, but it is worth the effort and can help you return to your usual day-to-day activities.



Whether organised screening programs (see page 5) are appropriate for you after treatment will depend on the type of cancer treatment you had. For more information, talk to your GP or cancer care specialist.

Caring for someone with cancer

You may be reading this booklet because you are caring for someone with cancer. What this means for you will vary. Being a carer can bring a sense of satisfaction, but it can also be challenging and stressful. Try to look after your own physical and emotional wellbeing. Give yourself some time out and share your concerns with a counsellor or your doctor. There is a wide range of support available to help.

Support services – Support services such as Meals on Wheels, home help or visiting nurses can help you in your caring role. You can find local services, as well as information and resources, through the Carer Gateway. Call 1800 422 737 or visit carergateway.gov.au.

Support groups and programs – Many cancer support groups and cancer education programs are open to carers as well as to people with cancer. Support groups and programs offer the chance to share experiences and ways of coping.

Carers Australia – Carers Australia provides information and advocacy for carers. Visit carersaustralia.com.au.

Support for young people – Canteen offers support to families with children aged 12–25 who have cancer, or close family member with cancer. Visit canteen.org.au.

Cancer Council – You can call Cancer Council 13 11 20 or visit your local Cancer Council website to find out more about carers' services.

▶ See our *Caring for Someone with Cancer* booklet.

Specific issues for LGBTQI+ carers

Caring can be challenging for everyone but LGBTQI+ carers may have added challenges. These include:

Discrimination – You may feel uncomfortable accessing services and support groups for fear they will discriminate against you because of your sexual orientation, gender or sex characteristics. This may be based on previous experiences with health professionals. You may worry that your relationship to the person you care for will not be recognised and you won't be included in decision-making. Some people deal with anticipated discrimination by hiding the nature of their relationship when accessing support.

Rights at work – If you are caring for someone in your family or household and working, you have the same rights as other employees. Talk to your employer about your caring responsibilities, and how they can support you with carer's leave and flexible working arrangements.

▶ See our *Cancer, Work & You* book.

Ask others for help – You don't have to do all the practical, emotional and financial tasks of caring alone.

Your friends and chosen family may be keen to help, especially if the person's family of origin has rejected them due to their sexual orientation, gender or intersex variation.

For resources designed specifically for LGBTQI+ carers, visit carergateway.gov.au/tips/tips-lgbti-carers. See pages 12–13 for ways to spot LGBTQI+ friendly services.

Financial help – Since federal reforms in 2008, everyone has the same rights and entitlements. This means you can access the Carer Allowance and Carer Payment if you meet the criteria. For more details, see servicesaustralia.gov.au.

Isolation and loneliness – You might feel lonely if friends stay away or if the LGBTQI+ communities aren't always as supportive as you'd assumed. Or you may feel too tired to socialise or enjoy your usual activities. Consider joining a support group or call QLife on 1800 184 527 for support.

Support and information

There are many sources of support and information to help you, your chosen family and carers. The availability of services may vary depending on where you live, and some services will be free but others might have a cost.

Useful organisations

Advance care planning

Advance Care Planning Australia
1300 208 582
advancecareplanning.org.au

Information about planning future health care, including advance care directives.

Cancer support and information

Cancer Council
13 11 20
[See back cover for local websites](#)

Telephone service for people affected by cancer, as well as practical support, legal and financial services.

Cancer Council Online Community
cancercouncil.com.au/OC

Share your thoughts and experiences with other people affected by cancer.

Cancer Council podcasts
cancercouncil.com.au/podcasts

Find information and insights in our series *The Thing About Cancer* and *The Thing About Advanced Cancer*, plus relaxation and meditation tracks in *Finding Calm During Cancer*.

Breast Cancer Network Australia
bcna.org.au

Provides information and support to people affected by breast cancer; offers LGBTIQ+ specific articles.

Canteen
canteen.org.au

Supports young people aged 12–25 affected by their own or a close family member's cancer diagnosis.

Cancer information and support continued

Can We canwe.org.au	LGBTQI+ specific information about cancer screening and prevention.
Prostate Cancer Foundation of Australia pcf.a.org.au	Provides information and support on prostate cancer; has online information for LGBTIQ+ people.

Carer services

Carer Gateway 1800 422 737 carergateway.gov.au	Practical information, support and useful resources for carers.
Carers Australia carersaustralia.com.au	National body working with state and territory carers associations to provide information and advocacy for carers.
Services Australia servicesaustralia.gov.au	Provides government payments and services; includes Centrelink and Medicare.

Complaints and regulatory organisations

Australian Health Practitioner Regulation Agency www.ahpra.gov.au	Registration body for health practitioners. Also investigates complaints about the conduct of health practitioners.
Australian Human Rights Commission 1300 656 419 humanrights.gov.au	Information and advice about Australia's discrimination legislation and disability standards; investigates complaints about unlawful discrimination.
Fair Work Ombudsman 13 13 94 fairwork.gov.au	Information and advice about Australia's workplace rights and rules, including awards, entitlements and national employment standards.
Office of the Australian Information Commissioner 1300 363 992 oaic.gov.au	Independent national body investigating privacy infringements and complaints.

LGBTQI+ specific

ACON acon.org.au	NSW-based health promotion organisation specialising in HIV prevention, HIV support and LGBTQ health (including cancer).
AGMC agmc.org.au	Advocates for the rights of multicultural and multifaith LGBTIQ communities.
Australian Professional Association for Trans Health auspath.org.au	Information for professionals involved in providing care for trans people; includes a national directory of health providers.
Bi Alliance bi-alliance.org	Online support and advocacy group, and events for the bi+ community.
Black Rainbow blackrainbow.org.au	Social network for Aboriginal and Torres Strait Islander people who identify as LGBQTIA+, sistergirl or brotherboy.
The Bottom Line thebottomline.org.au	Information on HPV and anal cancer for gay and other men who have sex with men.
Gender, Bodies and Relationships Passport lgbtiqhealth.org.au/passport	Tool to communicate information about your gender, body and relationships with health professionals and services.
Intersex Human Rights Australia ihra.org.au	Provides support, education and policy information, by and for people with intersex variations or traits.
LGBTIQ+ Health Australia lgbtiqhealth.org.au	National body for health organisations focused on LGBTIQ+ communities. Maintains list of organisations that provide health services for LGBTQI+ communities.
Minus18 minus18.org.au	Provides mental health support, peer mentoring and social events for LGBQTIA+ young people from all over Australia.
National LGBT Cancer Network (US) cancer-network.org	Information on cancer risk, screening and treatment for LGBTQI+ communities.

LGBTQI+ specific continued

qheadsace headsace.org.au/lgbtiqaplus	National mental health service for LGBTQIQA+ people aged 12–25.
ReachOut au.reachout.com/identity	Online mental health support for young people to talk about gender and sexuality.
TransHub www.transhub.org.au	Information about gender affirmation, hormones, and health needs, including cancer screening.

Referrals

DocDir docdir.org.au	Links to LGBTQ+ friendly health professionals and clinics.
DocLIST doclist.com.au	List of health professionals recommended by lesbian and bisexual women.

Sex and intimacy

Relationships Australia relationships.org.au	Provides programs to help people build positive and respectful relationships.
Society of Australian Sexologists societyaustraliansexologists.org.au	Regulates and accredits psychosexual therapists and sexuality educators; has option to search for a sexologist.

Telephone and online support

Beyond Blue beyondblue.org.au	Provides information and support for anxiety, depression and suicide prevention.
Lifeline 13 11 14 lifeline.org.au	24-hour telephone, text and online crisis support and suicide prevention.
QLife 1800 184 527 qlife.org.au	Provides peer support and referrals about sexuality, identity, gender, bodies, feelings or relationships through an anonymous online and phone counselling service. Available 3 pm–midnight.

Question checklist

Asking your health professionals questions can help you find the right support. You may want to include some of the questions below in your own list.

Treatment team

- Do you have an LGBTQI+ inclusive policy for patients and staff?
 - Have staff had training in meeting the needs of LGBTQI+ people?
 - Do you have experience dealing with LGBTQI+ people with cancer?
 - How will you keep my personal information confidential?
 - Can you amend my records with my gender, pronouns and preferred name?
 - Who can I talk to if I am not satisfied with my care?
 - I'm thinking of getting a second opinion. Can you recommend anyone?
-

Side effects

- What are the risks and possible side effects of each treatment? How can these be managed?
 - How will the treatment affect how I look and how my body works?
 - Will the treatment affect my sex life? Can I get support from someone who understands LGBTQI+ sex issues?
 - Will the cancer and treatment affect my fertility? What tests can I have to see if my fertility has been affected?
-

Support

- How can I connect with other LGBTQI+ people affected by cancer?
 - What financial and practical assistance is available?
 - Where can I get help with advance care planning?
-

Family and friends

- Will you include my partner/s and family, chosen and biological, in my care?
 - Can you help me talk to my family about what is happening?
 - Where can my partner/s, children and friends get help and advice?
-

After treatment

- Who will I see for follow-up appointments?
 - How often will I need check-ups after treatment?
-

Glossary

advance care planning

When a person thinks about their future health care and discusses their preferences with their family, friends and health care team. The written record of these wishes may be known by different names, such as an advance care directive, advanced care plan, or “living will”.

advanced cancer

Cancer that is unlikely to be cured. In most cases, the cancer has spread to other parts of the body (secondary or metastatic cancer). Treatment can often still control the cancer and manage symptoms.

androgen

A type of hormone that produces 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.

anxiety

Strong feelings of fear, dread, worry or unease.

asexual

A person who is not sexually attracted to other people.

bisexual

A person who is attracted to more than one gender.

body image

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

breast reconstruction

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

cervix

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

chemotherapy

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

chosen family

A group of people who become family by developing close relationships and connections even though they may not be related biologically or legally.

chromosomes

Threadlike structures that contain sets of instructions known as genes. Most cells in the human body have 23 pairs of chromosomes.

cisgender

A term for a person whose gender matches the sex assigned at birth. Also known as cis.

climax

The peak of sexual response. Also known as orgasm.

clitoris

The main sexual pleasure organ for ciswomen and people with a vulva.

coming out

Disclosing your sexual orientation or gender to other people.

default substitute decision-maker

A person who makes decisions on your behalf if you become incapable of making them yourself.

depression

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

discrimination

When someone is treated less favourably because of certain protected attributes, such as being LGBTQI+ or having a disability.

distress

Emotional, mental, social or spiritual

suffering. Distress may range from feelings of vulnerability and sadness to stronger feelings of depression, anxiety, panic and isolation.

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 orgasm.

endosex

People who are not intersex.

erectile dysfunction

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

erogenous zones

Areas of the body that respond to sexual stimulation.

female

In typical thinking about biology, people born with a uterus, cervix and/or ovaries.

fertility

The ability to conceive a child.

gay man

A man (cisgender or trans) who is attracted to other men.

gender

The sense of whether you are a man, woman, non-binary, agender, genderqueer, genderfluid, or a combination of one or more of these.

gender-affirming treatment

Having surgery or taking hormones to affirm your gender.

gender diverse

Describes a range of genders.

gender dysphoria

Feeling uncomfortable or distressed about your gender. Gender dysphoria is often caused by other people's reactions.

genitals

The sex organs. Often used to mean the external sexual organs (e.g. penis, vulva).

gynaecological cancers

Cancers of the following reproductive organs: cervix, fallopian tubes, ovaries, uterus, vagina and vulva.

health services

Organisations such as screening clinics, GPs, hospitals and cancer treatment centres that provide medical care.

heterosexual

Attracted to people of the opposite gender. Also known as straight.

homosexual

Attracted to people of the same gender. See also gay man and lesbian.

hormone replacement therapy

Drug therapy that supplies the body with hormones that it is not able to produce naturally.

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.

hysterectomy

The surgical removal of the uterus. The cervix, ovaries and fallopian tubes may also be removed, depending on the type of hysterectomy.

immunotherapy

Drugs that use the body's own immune system to fight cancer.

impotence

See erectile dysfunction.

incontinence

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

infertility

The inability to conceive a child.

intersex

A term used to describe a person born with sex characteristics (physical, hormonal or chromosomal) that don't match the typical understanding of the male or female body.

intimacy

Being physically and emotionally close to someone.

lesbian

A woman who is attracted to other women.

LGBTQI+

A commonly used acronym referring to those who identify as lesbian, gay, bisexual, transgender, queer or questioning, or other sexualities (such as pansexual or asexual), as well as intersex. Other acronyms may also be used, such as LGBTQIA+, LGBTIQ.

libido

Sex drive/sexual desire.

lymph nodes

Small, bean-shaped structures found in groups throughout the body. They help protect the body against disease and infection. 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.

male

In typical thinking about biology, people born with a penis and/or testicles.

mammogram

A low-dose x-ray of the breast or chest; used to screen for breast cancer.

mastectomy

Surgery to remove all breast tissue.

masturbation

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

menopause

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

minority stress

Ongoing stress arising from the stigma, discrimination and hostility minority groups such as LGBTQI+ people face.

misgender

Using the wrong pronouns to refer to a person.

non-binary

Identifying as a gender that is neither man nor woman. This is an umbrella term for any number of gender identities that sit within, outside of, across or between the spectrum of woman or man. A non-binary person might identify as gender fluid, trans masculine, trans feminine, agender, bigender, etc.

oestrogen

A sex hormone made mainly by the ovaries. It is also used in gender-affirming hormone therapy and hormone therapy for cancer.

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 (plural: ovaries)

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

pansexual

A person who is attracted to all people.

penetrative sex

Insertion of a body part or sex toy into the vagina, anus or mouth.

penis

The main external sex organ in cismen and people with a penis. Urine and semen pass out of the body through the penis.

person-centred care

Care that is respectful of, and responsive to, the preferences, needs and values of the individual patient.

person responsible

A person who, under law, can make decisions on behalf of a patient who cannot make their own decisions and has not appointed someone to act on their behalf.

premature/early menopause

Menopause that occurs before the age of 40.

premature ejaculation (PE)

The inability to delay ejaculation.

progesterone

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

prostate

A gland that is part of the reproductive system for people born with a penis. It produces fluid that makes up part of semen.

prostatectomy

Surgery to remove all or part of the gland known as the prostate.

prosthesis

Artificial replacement for a removed or damaged body part.

queer

A range of non-normative genders and sexualities. Although once used as a slur, queer now also encapsulates political ideas of resistance to heteronormativity and homonormativity and is sometimes used as an umbrella term to describe the full range of LGBTQI+ identities or used to describe people with diverse gender or sexual orientation.

radiation therapy

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

reproductive system

The organs needed for producing a baby. May include the ovaries, fallopian tubes, uterus, cervix and vagina, and the testicles, prostate and penis.

screening

An organised program to identify disease in people before any symptoms appear.

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, and self-stimulation or masturbation.

sex characteristics

A person's physical characteristics, including sexual anatomy, reproductive

organs, hormonal patterns and chromosomal patterns. Some people are born with variations of these sex characteristics, which are called intersex variations.

sex hormones

The hormones that control sexual development, arousal and reproduction.

The main sex hormones are oestrogen, progesterone and testosterone.

sexual orientation

How a person thinks about their sexual identity, how they behave and the people they are attracted to. See also asexual, bisexual, heterosexual, homosexual, pansexual.

Under Commonwealth discrimination legislation, the term refers to sex only; under discrimination legislation in some states and territories, it refers to gender.

side effect

Unintended effect of a drug or treatment.

sperm

The sex cell made in the testicles.

stoma

A surgically created opening to the outside of the body.

substitute decision-maker

A person who you choose to make decisions about your medical treatment if you become incapable of making them yourself. May be known as an enduring guardian, enduring power of attorney or medical treatment decision maker. See also default substitute decision-maker.

targeted therapy

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

testicles (also called testes)

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

testosterone

A sex hormone produced by the testicles.

It is also used in some gender-affirming hormone therapy.

top surgery

Removal of breast or chest tissue. A type of gender-affirming surgery.

transgender (trans)

A term for a person whose gender is different from the gender assigned at birth.

urethra

The tube that carries urine from the bladder, as well as semen from the testicles, to the outside of the body.

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 dilator

A tube-shaped device made from plastic or silicone that is inserted into the vagina. It is designed to gently stretch the vaginal walls.

vaginal stenosis

Narrowing of the vagina.

vas deferens

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

vulva

The external sexual organs (genitals) in ciswomen and people with vaginas. It includes the mons pubis, labia majora and minora, and clitoris.

Can't find a word here?

For more cancer-related words, visit: cancercouncil.com.au/words.

References and booklet reviewers

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Booklet reviewers

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How you can help

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

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

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

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

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

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

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



Cancer Council

13 11 20

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

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

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

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



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



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

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

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

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Cancer Council SA
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Cancer Council WA
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Cancer Council NT
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