

LIVING WITH CANCER AND BEYOND



Contents

Finding out	4
What is cancer?	5
Common questions	5
Talking about cancer	6
Who to tell	6
How to tell people	7
Telling children about cancer	7
Let's talk about feelings	8
Grief and loss	8
Finding a way through	8
Religious beliefs and spirituality	10
Where to find support	10
Managing other people's expectations	11
When you're LGBTQ+	12
When you're born with intersex variations	14
Taking care of yourself	16
Self-care	16
Drugs and alcohol	17
Sex and cancer	17
Practical stuff	18
School and study	18
Work	19
Money matters	20
Legal stuff	21
Planning travel	22
Getting the right information	23
What happens in hospital?	24
Admission process	24

Mobility in hospital	24
Visitation policies	24
Support for rural patients	24
Transitioning home	24
Managing relationships and cancer	26
Support for parents and carers	26
Sibling dynamics	26
Friendships	27
Partner relationships	27
Starting new relationships	27
Dealing with changes to your body	28
Late effects of cancer treatment	28
If cancer returns	30
Treatment decisions	30
When treatment doesn't work	31
Getting the right information	31
Advanced treatment decisions	31
Recording your treatment wishes	31
Making plans	31
Beyond cancer	32
Redefining your life plans	32
Your identity	32
Uncertainty and worry	33
Relationships after cancer	33
Pressure from others to 'Get over it'	33
More information and support	34
LGBTQI+ specific	34

Finding out

If you are reading this, you may have been told you have cancer. This can be a tough time, but keep the following in mind:

- Most young people survive cancer
- You're not alone
- It's not your fault
- (Correct) knowledge is power
- Hang on to hope
- Let your feelings out
- Things usually get easier
- Everyone's situation is different

- You can get answers and support

Canteen provides a free and confidential counselling service.

You can also ask your doctor to recommend a counsellor or contact your nearest Youth Cancer Service (youthcancer.com.au).

Specialist treatment and support for young people with cancer aged 15-25 is provided by the Youth Cancer Services (YCS) based in major hospitals throughout Australia.



What is cancer?

Cancer is a disease where some cells grow abnormally and form a mass called a tumour. Tumours can be benign (non-cancerous) or malignant (cancerous). Benign tumours don't spread and can often be removed. Malignant tumours can spread to nearby tissues and other organs (metastasis). Leukemia, a cancer of the bone marrow and blood, doesn't form tumours.

There are over 200 types of cancer, some more common in young people than adults. For more information, visit Cancer Council (cancer.org.au).



Common questions

How do they know I have cancer?

Common symptoms include extreme exhaustion, headaches, blurry vision, and cold or flu symptoms. Sometimes, cancer is found during tests for another illness. Doctors use x-rays, MRI scans, or blood tests to diagnose cancer.

How did I get cancer?

Cancer is common, affecting about one in three people in Australia, but it's rare in young people. Each year, about 1,100 Australians aged 12 to 25 are diagnosed. The causes are mostly unknown. You can't catch it or give it to someone else. Lifestyle choices like smoking or drinking are unlikely causes at a young age.

Can they cure it?

Most young people survive cancer. However, some cancers cannot be cured. The prognosis depends on the type, location, and stage of cancer. Talk to your doctor for specific information and support.

How long does treatment take?

Treatment duration varies. Some cancers take 3 months to treat, others may take 3 years or more, with varying side effects.

For support, visit Cancer Council or contact your doctor.

Talking about cancer

Cancer is a tough topic. Not all families talk openly about it. Here are some tips to help:

- **Timing:** Find the right time and way to discuss it.
- **Content:** Decide what you want people to know and what support you need.
- **Contacts:** Consider who else knows and who they can talk to.
- **Follow-Up:** Decide how you want them to stay in touch after the initial conversation.

Who to tell

Deciding who to tell can be difficult. It's your choice who to inform and how much to share. Here are some reasons to tell and not to tell:

Reasons to tell

- Gain support from trusted people.
- Feel less alone.

Reasons not to tell

- You may feel embarrassed.
- You might not want to repeat the same story.
- You don't want your life defined by cancer.
- People might share their own cancer stories.

Who you have to tell

- **Students:** There's no legal obligation to inform your school, but it can be helpful if side effects impact your studies.
- **Employees:** Informing your boss or HR can make it easier to take time off.



How to tell people

- **Practice:** Write down or read from a script.
- **Acceptance:** Be prepared for a range of reactions.
- **Patience:** Take your time and don't feel pressured to share everything in one conversation.
- **Distraction:** Talk while doing something else to ease the focus.
- **Delegation:** Allow friends, family, or teachers to tell others if you prefer.
- **Handling Questions:** Direct insensitive questions to reliable sources like the Cancer Council website ([cancer.org.au](https://www.cancer.org.au)).

Sharing online

Social media can be a way to share your diagnosis, but consider privacy. Discuss with friends and family what you want shared online.

If talking is too hard

- **Alternative Expression:** Draw, write, play music, keep a journal, or send texts.

- **Counselling:** If talking is difficult, consider speaking to a counsellor. Contact Canteen (canteen.org.au/counselling) for free services.

Telling children about cancer

Children will sense something is wrong. It's best to be honest:

- **Feelings:** Allow children to express their emotions.
- **Information:** Share in small, digestible chunks.
- **Reassurance:** Ensure them it's no one's fault and not contagious.
- **Questions:** Encourage them to ask questions.

Connect with other parents through Parenting through Cancer (parentingthroughcancer.org.au). Download "Talking to Kids About Cancer" from cancercouncil.com.au or call 13 11 20 for a free copy.

Let's talk about feelings

Grief and loss

Understanding grief and loss can be complex. Reasons for grief include feeling disconnected from your body, missing your old life, and changes in relationships. People grieve differently; some become practical, while others openly express emotions. It's crucial to balance practicality with emotional expression. Common feelings include shock, sadness, and uncertainty. Grief can make life feel purposeless, leading to changes in behaviour and energy levels. It comes in waves, with good and bad days, and may not lessen over time. Instead, it can become a part of you, shaping how you grow and navigate life.



People tend to believe that grief shrinks over time



What really happens is that we grow around our grief

Finding a way through

During tough times it can be hard to cope, and looking for positive coping mechanisms is essential. It's important to find that works best for you. Strategies like journaling, maintaining routines, exercising, trying new activities, meditating, surrounding oneself with supportive individuals, staying engaged in usual activities, ensuring adequate rest, and joining support groups can help manage overwhelming feelings and grief effectively.

It's important to find what works best for individual needs to navigate through challenging emotions and situations.



Religious beliefs and spirituality

A cancer diagnosis can prompt reflection on spiritual beliefs. Spirituality encompasses how individuals find meaning in life through various aspects like nature, culture, and religion. Cancer challenges perspectives on life and death, encouraging exploration of beliefs. Religion can offer solace during this time but may also spark questioning. Going through something like cancer can influence young people to reassess their faith. Changing religious views might lead to familial conflicts or newfound interest in spirituality. Regardless of traditional

religious involvement, exploring spirituality can provide understanding and meaning during adversity.

It's natural to seek answers and comfort in spirituality amid the challenges of cancer.

Where to find support

Canteen offers counselling and individual support (canteen.org.au). You can also contact Kids Helpline (kidshelpline.com.au, 1800 55 1800) or Lifeline (lifeline.org.au, 13 11 14).

If you notice changes in your life that are getting difficult to manage talk to your GP or treatment team.

Managing other people's expectations

Having cancer may be one of the biggest and scariest things that you ever face, and it's natural to be worried and upset and to show it.

So, this is a reminder that it's okay to:

- still get angry with the people you love and not be the perfect child, sibling, friend or partner
- not feel brave all the time or think that the whole experience will be good for you
- not feel positive all the time
- not feel 'lucky' that the cancer has been cured
- not feel like you've been through a life-altering transformation
- not feel special.





When you're LGBTQ+

For LGBTQ+ individuals facing a cancer diagnosis, navigating healthcare can be complex. You have the right to receive care in a culturally safe and inclusive health setting.

Understanding your rights

As a patient you have rights as outlined in the Australian Charter of Healthcare Rights, including:

- Access to services tailored to your needs.
- Affirmation and respect for your sexual orientation and gender identity.
- Inclusion of chosen family in decision-making.
- Confidentiality of personal and health information.

For more information, visit safetyandquality.gov.au/your-rights.

Common concerns

Identity exploration

- Cancer can make you re-examine your sense of identity.
- Treatment side effects can affirm or challenge your identity.
- It's normal to experience a range of emotions during this process.

Feeling isolated

- Cancer diagnosis may exacerbate feelings of isolation, especially if you already feel different due to your sexual orientation or gender identity.
- You can seek support from LGBTQ+ organisations like QLife and Minus 18.

Worrying about coming out

- Deciding whether to disclose your sexual orientation and/or gender identity to healthcare professionals can be stressful.
- You only have to disclose information to those you feel comfortable with.
- Sharing this information can help healthcare providers better understand your needs.

Sharing your name and pronouns

- Introduce yourself with your preferred name and pronouns.
- Wearing a pronoun badge can help remind others of your identity.
- Address misgendering promptly and consider requesting to work with a different healthcare team if it persists.

Introducing partners and family

- Encourage your partner(s) and family to attend appointments to convey their importance to your healthcare providers.

Privacy concerns

- Your doctor should keep information about your gender identity and/or sexual orientation private. Let them know who you are comfortable for them to share this information with.
- You have the right to address breaches of confidentiality.



Addressing medical interventions

No one should be treated differently due to any part of their identity. If you're unhappy about the way a health professional or service has treated you, you have options:

- Lodge a complaint with the Australian Human Rights Commission or state/territory discrimination agencies.
- Consider changing healthcare providers if necessary.
- Seek support from the health service manager or social worker.

If undergoing medical interventions to affirm your gender

- Discuss potential impacts of cancer treatment on gender-affirming procedures with your healthcare provider.
- Seek clarity on how cancer treatment may affect your transition plans.

When you're born with intersex variations

The term intersex refers to people who are born with genetic, hormonal or physical sex characteristics that do not fit neatly with the medical or social norms for male and female bodies. These variations of sex characteristics may be apparent at birth or much later. There are at least 40 known variations and may include complete androgen insensitivity; 46,XY complete gonadal dysgenesis (Swyer syndrome); and 47,XXY (Klinefelter syndrome).

You don't need to tell your health professionals that you have an intersex variation, but knowing this may help them give you the information that is right for you. And depending on the type of cancer you are diagnosed with, knowing about your intersex variation may help guide your care and treatment.

If you haven't felt in control of decisions about your body, let your health professionals know that it's important that you are involved in decisions about your treatment.

You may can help with building trust with your healthcare team.

For more information and support, visit Intersex Human Rights Australia at ihra.org.au.



Taking care of yourself

Self-care

Eating well

There will be times during your treatment when you don't feel like eating. But a good diet is important. Food is the fuel your body needs to keep it running – and you need extra fuel during cancer treatment.

Speak to the hospital dietitian for advice on what foods you should eat.

Cancer Council has more information about eating well after a cancer diagnosis. Visit cancercouncil.com.au and search for 'eating well'.

Physical activity

Exercise can help:

- heal your tissues and organs that have been damaged by treatment
- give you more energy
- you have a better night's sleep
- keep your bones strong – some treatments can reduce your bone density, making them easier to break
- you cope with the stress of cancer and its treatment
- increase feel good endorphins

Before starting any exercise program check with your GP or treating healthcare team about any precautions you should take.

Infections

Some cancer treatments, such as chemo, can reduce your immunity and increase your risk of picking up an infection. To lower your chances of getting an infection you should:

- stay away from people who are sick – even if it's just a cold or flu
- ask friends and relatives to tell you if they are sick or have been in contact with someone who is
- wash your hands often and well
- consider wearing a surgical face mask if going out
- make sure your food has been washed and cooked properly
- use sterile procedures when you clean your central lines
- call your doctor straight away if you develop a temperature of 38°C or higher or other symptoms like chills or shivering, sore throat, rash, earache or upset stomach.

Getting enough sleep

Even though you may feel very tired a lot of the time, many people with cancer find it hard to sleep. Worry, pain, fevers, coughing, nausea and treatment drugs might affect your sleep.

ReachOut has great tips on how to sleep well. Visit au.reachout.com and search for 'sleep issues'.



Drugs and alcohol

Drugs and alcohol don't mix well with cancer. To give your body the best chance to deal with the cancer, it is important to be straight up with your treatment team about what drugs you may be using or have used in the past. This includes illegal drugs (such as cannabis, cocaine or ecstasy), and legal drugs (alcohol, cigarettes and vapes).

Cancer and its treatment can impact how your body feels – your energy levels might be down and you may struggle to fight off infections. Drugs and alcohol will only make this harder. They can:

- make chemo, radiation therapy or other treatments not work as well
- increase the impact of side effects
- increase your chances of getting things like chest infections and other respiratory (breathing) problems
- result in other infections, especially if you are injecting or sharing needles

- affect your mood and behaviour, making it harder to deal with the physical and emotional challenges of cancer.

Sex and cancer

Cancer treatment might have you feeling washed out and not having much energy for many months or even longer. You may lose your interest in sex, feel unattractive or worry that you will never be able to be sexually active. The main thing to remember is that how you feel right now is temporary and it's really likely to pass in the future.

Cancer Council has more information about sex and cancer. Visit cancercouncil.com.au and search for 'sexuality'.

If you are still concerned or worried about any symptoms you are experiencing, talk with your treatment team.

Practical stuff

School and study

It's normal to feel nervous as well as excited about returning to school or uni. Before you return, reach out to the school to find out what to expect, and if you're comfortable, let your teachers know about your circumstances.

Find out more at canteen.org.au/ecs.

Friends at school, uni or TAFE

On the first day of school or uni, having a friend for support can help. If you're uncomfortable with questions or experience teasing, let a parent, teacher, or student services know. Talking to a counsellor can also aid in adjusting to school or dealing with treatment issues.

Keeping up

Even after returning to school, you may miss classes for appointments or treatment. To manage this, you can ask a friend to take notes, request teachers to email assignments, and prioritise essential work with your teacher. If you travel for treatment, consider distance education or hospital school services. Canteen's Education and Career Support Service (canteen.org.au/ecs) can assist.

Marks

After treatment, studying can be harder, and you may get lower marks due to absences or difficulty concentrating. You may feel the

need to work harder or change your educational goals. Teachers and parents or carers can help support you during this time.

Years 11 and 12

If you are doing your final school exams, it can help to speak to your teachers or the school counsellor about applying for 'special consideration'.



Uni and TAFE

Cancer treatment and side effects may impact your choice of course and study method. Concerns include stress on your body, meeting assessment requirements, health unpredictability, fitting in, physical access, and completing specific tasks. Distance learning might be an option. Universities and TAFEs offer support services for adjustments like extra exam time, lecture notes, note-takers, assistive technology, and special assessment consideration.

For help, contact school welfare staff, or university/TAFE student services (search 'Accessibility'). If you have a permanent disability, check the National Disability Insurance Agency (ndis.gov.au) for support. Student centers provide various services, including counseling, financial aid, tutoring, career advice, health services, housing, childcare, employment services, and support for Aboriginal and Torres Strait Islander students.

Work

Returning to work can boost your confidence and independence, restoring your routine. Here are some tips for going back:

- **Know your limits:** Avoid doing too much too soon, take breaks, and consider adjusting tasks, shift lengths, or hours. Working from home might help.

- **Keep your boss informed:** Communicate about follow-up appointments, treatments, and needed rest days in advance.
- **Adjust your schedule:** Align work hours with your energy levels.
- **Privacy:** Decide how much to share about your cancer with colleagues; your boss can't share information about you without your consent.

For getting a new job:

- **Legal rights:** Employers can't refuse to hire you because of your medical history, and you're not obliged to disclose it.
- **Confidentiality:** Employers must keep medical information private but can ask about your ability to perform job-related tasks.
- **Documentation:** Consider providing a doctor's letter explaining your health status and work capability.
- **Resume tips:** Organise your resume by experience and skills instead of dates to explain gaps due to treatment.
- **Career advice:** A career counselor can help with resume writing and interview preparation.

Looking for work takes time—be kind to yourself and incorporate fun and exercise to stay motivated.

Canteen can help you with this, go to www.canteen.org.au/ecs.



Money matters

Cancer can bring financial concerns, but support is available.

Treatment costs vary; with Medicare, public hospital treatment is free but may involve wait times. Private insurance offers more control over where and when you will be treated, and the choice of doctor, but it may incur fees. Uninsured individuals can still access public health care. Talk to doctors, hospitals, and insurers for accurate information.

In Australia, health funds can't discriminate based on health status. Complaints can be made to the Commonwealth Ombudsman. Having

a cancer history typically won't affect access to financial services, but insurance may require shopping around.

Financial aid from government agencies and charities can cover rent, carer payments, medication costs, and more. Cancer Hub's navigators assist with financial and emotional support. For Australian Government assistance, contact Centrelink.

Rural areas offer travel and accommodation support for cancer patients; criteria vary by state. Consult your treatment team or cancerhub.org.au for details.

Legal stuff

Age of consent

Regardless of age, you have rights. At 16, you can participate in your care, making treatment decisions if you understand the implications. Under 18, parents or guardians are primarily responsible, but your input should be considered. At 18, you're legally an adult, able to make medical decisions autonomously.

Making a Will

Creating a Will at 18 ensures your wishes regarding assets and children are honored after death. Legal advice is beneficial. If under 18, marriage, or plans to marry, allows you to create a Will. Otherwise, you can document your wishes and entrust them to a reliable person.

Disability discrimination

Disability discrimination occurs when unfair treatment or harassment is based on illness or its effects. Examples include job denial, unfair treatment at work, or university/TAFE enrolment issues. It's illegal to discriminate against cancer patients. If you face unfair treatment, it is important that you bring it up.

Getting legal advice

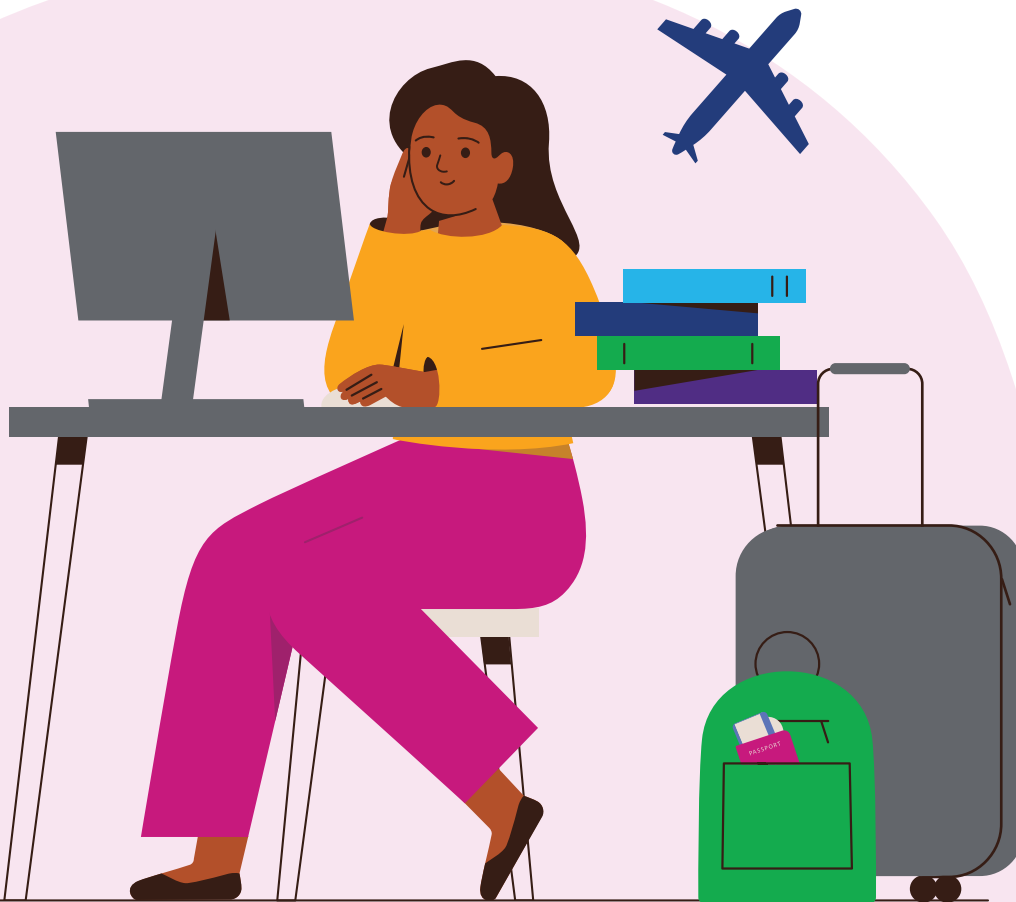
For legal advice, consult reputable organisations or Legal Aid in your state. Only accept advice from professionals. If you feel overwhelmed, confide in someone about your concerns.



Planning travel

Discuss travel plans with your healthcare team. Depending on your cancer type and treatments, you might face vaccination restrictions. Some countries restrict certain medicines; your agent or the Australian Embassy can provide guidance.

Carry medical letters for specific treatments. Keep printed and digital medical records, and consider travel insurance, understanding that costs and coverage vary based on treatment status, cancer type, and age.



Getting the right information

Understanding your condition empowers you in dealing with cancer. Whether you prefer detailed information or a general overview, it's your choice.

Don't hesitate to ask your treatment team questions such as the type of cancer, its spread, necessary tests, treatment impact, costs, and support available. Clarify if your loved ones can stay with you in hospital and how to address any arising issues.

Ask about LGBTQI+ policies for patients and staff, inclusivity training, experience with LGBTQI+ cancer

patients, confidentiality, record amendments for pronouns and preferred names, and interactions between cancer treatment and gender affirmation hormones.

When using the internet for health information, verify sources. Beware of outdated or misleading content. Seek information from reputable cancer organizations like Cancer Council and Cancer Australia. Consult your doctor regarding online findings, especially if claims seem too good to be true.

What happens in hospital?

Admission process

Upon admission, expect to interact with administrative staff and a range of healthcare professionals. These may include oncologists, surgeons, and social workers. You can request private discussions with doctors or nurses if needed.

Mobility in hospital

Your mobility in hospital depends on your cancer type and treatment. Your healthcare team will advise you on mobility levels during your stay.

Visitation policies

Hospital visitation rules vary. Consult your healthcare team for specifics.

Support for rural patients

Being away from home can be challenging. Cancer Hub offers practical and emotional support for travel and accommodation.

Transitioning home

Leaving the hospital can be daunting. Establishing a routine and seeking support from family, friends, and healthcare professionals can ease the transition. Ongoing support is available from your healthcare team and organisations like Canteen.



Managing relationships and cancer

Cancer diagnoses can strain relationships, affecting parents, siblings, friends, partners, and new acquaintances. These bonds, once a source of comfort, can become sources of stress and uncertainty during treatment. Navigating these shifts requires understanding and support from both parties involved.

Support for parents and carers

Parents and caregivers often undergo immense emotional and logistical challenges when their child is diagnosed with cancer. Canteen provides essential support for parents and carers, including counselling and access to an online community through parentingthroughcancer.org.au. Additionally, practical support is available through Cancer Hub, an initiative by Canteen, Camp Quality, and Redkite, which offers financial assistance and emotional support for families. There are support and resources for parents and carers to navigate challenges, they don't need to do this alone.

Sibling dynamics

Siblings of cancer patients experience a wide range of emotions, including fear, anger, jealousy, guilt, and loneliness. While much of the focus may be on the diagnosed individual, siblings often feel overlooked and neglected. Their feelings should be

acknowledged so they can get the support they need. Canteen offers support specifically tailored to siblings, providing them with a safe space to express their emotions and connect with others who understand their experiences.

Friendships

Friends of cancer patients may struggle to cope with the diagnosis, leading to strained relationships. The stress and emotional upheaval of treatment can make it difficult for friends to know how to offer the right support effectively. While some friends may withdraw or avoid discussing the diagnosis altogether, others may inadvertently say or do things that are hurtful. Understanding their perspective can help guide communication and foster mutual support. Communicating openly can help patients and friends be there to support and understand each other during this challenging time.



Partner relationships

Cancer can profoundly impact partner relationships, causing emotional upheaval and communication challenges. Partners may experience a range of emotions, including fear, sadness, worry, anger, overwhelm, and confusion. The dynamics of the relationship may shift as both partners navigate the challenges of cancer treatment together. Partners should communicate openly and honestly with each other, expressing their needs, fears, and concerns. Seeking professional counseling can provide additional support and guidance as couples navigate this difficult journey together.

Starting new relationships

Despite the challenges of cancer treatment, finding opportunities to socialise and meet new people can be beneficial for patients. Engaging in social activities can boost self-confidence and provide a sense of

normalcy amidst illness. While the prospect of starting new relationships may seem daunting, it's essential for patients to remember that they are more than their diagnosis. Taking care of one's emotional and social well-being is an integral part of the healing process.

Cancer diagnoses can have far-reaching effects on relationships, but with understanding, communication, and support, individuals can navigate these challenges and emerge stronger together.



Dealing with changes to your body

Everyone faces confidence and body image issues, especially during teenage and young adult years. Cancer and its treatment can intensify these feelings, altering how your body looks, feels, and works. Changes like body shape fluctuation, hair loss, or scarring can make you feel different and uncomfortable.

You might experience:

- Loss of confidence and self-esteem
- Shyness and withdrawal
- Frustration
- Anger
- Nervousness

- Embarrassment or shame
- Grief
- Fear
- Worry

It's normal to be concerned about your appearance. To cope:

- Experiment with wigs, hats, makeup, or new clothes.
- Talk about your feelings.
- Eat healthily, sleep well, and exercise.
- Spend time with supportive people.
- Remember, cancer doesn't define you.

Late effects of cancer treatment

"Late effects" are health issues that appear years after cancer treatment ends and are not a sign of cancer returning. Not everyone experiences them.

Possible late effects include:

- Lung, heart, kidney, and liver problems
- Secondary cancers
- Cataracts
- Fertility issues
- Bowel problems
- Thyroid issues
- Tooth decay
- Osteoporosis

- Memory and concentration problems

Managing Late Effects:

- Maintain a detailed record of your diagnosis, treatments, and care plan for future doctors.
- Attend follow-up appointments and report any symptoms.
- Maintain a healthy lifestyle to possibly reduce the risk of late effects. This includes protecting yourself in the sun, avoiding smoking and alcohol, and exercising regularly.

For more information, visit the Peter MacCallum Cancer Centre petermac.org/services/treatment/late-effects.



If cancer returns

Although doctors will give you the very best treatment, there is a chance the cancer will come back. This is known as relapse. It simply means that a small number of cancer cells survived the treatment.

It is possible to develop a new cancer that has nothing to do with your original cancer, but this doesn't happen very often.

Visit cancercouncil.com.au and search for advanced cancer for more information.

Treatment decisions

Things to consider when making decisions about what treatment to have include:

- What impact will it have on your quality of life?
- What side effects – both long and short term – will you get?
- What type/s of treatment will you accept?
- Your prognosis – which explains the likely course and outcome of the cancer.

When treatment doesn't work

Sometimes treatment fails, and being told cancer cannot be cured is devastating. A life-limiting or terminal illness means cancer is likely to cause death. In these times, Canteen offers support, including counselling, resources to make the most of life, and connections with others facing incurable cancer. Learn more at Canteen.

Getting the right information

Ask your healthcare team important questions such as:

- Why did this happen?
- Are there no more treatments to try?
- Can I get a second opinion?
- How long do I have?
- What will it feel like? Will it hurt?
- Will I be aware of what is happening?

Advanced treatment decisions

You'll need to make crucial decisions about your treatment, including:

- Type and location of treatment
- When to stop treatment
- Whether to treat infections or attempt resuscitation

Discuss these choices with your family and treatment team to reduce stress later.

Recording your treatment wishes

You'll need to make crucial decisions about your treatment, including:

Advanced care planning ensures your medical treatment preferences are respected if you become unable to communicate. Learn more at Advance Care Planning Australia or talk to Canteen or your treatment team.

Making plans

After the initial shock, you may start planning things you want to do or say. Consider:

- Is there something you've always wanted to do or see?
- Are there messages you want to share with loved ones?
- Is there someone special you want to meet?
- Are there decisions you want to make now?
- How do you want to be remembered?
- Do you want to leave letters or instructions for special occasions?
- How do you envision your funeral, celebration, or memorial?
- Would you prefer to be buried or cremated?
- Have you made a Will?
- Have you communicated your end-of-life treatment wishes to your family?



Beyond cancer

During treatment, survival is the primary focus, but what happens after it ends? Entering the phase known as “survivorship,” you may face long-term impacts such as health issues like infertility, low self-esteem due to physical reminders like scars, health anxiety, and feeling the need to catch up with peers in education, career, and relationships. There’s also pressure to feel grateful despite missing out on much.



Redefining your life plans

Post-treatment, consider redefining your life rather than reconstructing it. Take time to reflect on whether you want things to look the same as before. Some plans and goals may need rethinking due to changes in your body, energy levels, or emotional state. You might have to adjust your career aspirations or discover new ones inspired by your cancer experience. It’s normal to feel uncertain about the future. Write down short-term and long-term plans, and seek advice from family, friends, career advisors, or social workers. The key is to do what feels right for you. Visit Canteen for more information.

Your identity

Cancer can alter how you see yourself. Changes in appearance, self-esteem, confidence, and sexual health may affect your identity. Your roles in relationships and family dynamics may shift, and you might feel more mature and stronger. People might treat you differently, and ‘cancer’ could start defining your identity. To maintain your sense of self, engage in activities you enjoyed before cancer, like school, work, and socialising.

Uncertainty and worry

Worrying about cancer’s return is normal but can be exhausting. It’s important to acknowledge and work through these feelings. Be kind to yourself and don’t ignore your emotions.

Relationships after cancer

Family

Families often expect a return to normalcy post-treatment, but adjustments are necessary. Be patient as your family adapts. It may be challenging for them to relinquish control or discuss cancer. Establish new routines and continue supporting each other.

Friends

Your friendships may change, with some becoming closer and others more distant. You may rethink or end some friendships as your interests evolve. You can meet people with similar values through clubs, teams, or online communities. Be honest about the kind of person you want to be and the company you want to keep.

Partners

Post-treatment, concerns about attractiveness and forming new relationships are common. You may wonder how and when to disclose your cancer history, especially if it affects fertility. To build new relationships:

- Participate in activities to meet people and practice social skills.
- Connect with other survivors to discuss dating experiences.

- Talk to friends, family, or a counselor about your concerns.

Pressure from others to ‘Get over it’

Well-meaning statements like “time to move on” can feel dismissive. Explain to others that the cancer experience is ongoing and that you need time and space to cope. If you’re struggling, it’s okay to ask for help. Consider:

- Experimenting with new routines.
- Exploring personal and professional development opportunities.
- Acknowledging significant dates and the losses experienced.
- Focusing on positive changes since diagnosis.
- Joining support groups to share experiences and support others.
- Recognising the change, loss, and grief from cancer.
- Prioritising self-care with a healthy diet and regular exercise.

More information and support

Canteen Connect

canteenconnect.org

Cancer Council

cancercouncil.com.au

13 11 20

CancerHub

cancerhub.org.au

1800 945 215

Youth Cancer Services

youthcancer.com.au

Specialist treatment and support for young people with cancer aged 15-25 is provided by the Youth Cancer Services (YCS) based in major hospitals throughout Australia.

Getting Cancer Young – YouTube channel

<https://www.youtube.com/channel/UCIdlYhxjsF4EdjXDsbUm-Cg>

Peter MacCallum Cancer Centre

petermac.org/services/treatment/late-effects

Parenting through Cancer

parentingthroughcancer.org.au

DocDir website

docdir.org.au

Advance Care Planning Australia

advancecareplanning.org.au

BlaQ

blaq.org.au

Kids Helpline

kidshelpline.com.au

1800 55 1800

Lifeline

lifeline.org.au

13 11 14

ReachOut

au.reachout.com

headspace

1800 650 890

Mental Health Line

1800 011 511

LGBTQI+ specific

QLife

Call 1800 184 527 (3pm to midnight daily) or visit qlife.org.au to chat online.

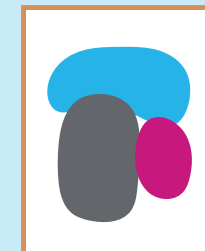
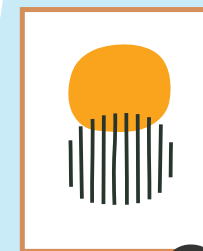
TransHub

transhub.org.au

Intersex Human Rights Australia

irha.org.au

This book is intended as a general introduction to the topic and should not be seen as a substitute for advice from doctors or other health professionals. All care is taken to ensure that the information contained here is accurate at the time of publication.



**Canteen is here if you're
12-25 and cancer has turned
your world upside down.**

canteen.org.au

