



Understanding Chemotherapy

A guide for people with cancer,
their families and friends

A large yellow shape, resembling a stylized drop or a large letter 'C', occupies the lower half of the page. A purple circle is positioned on the right side of this shape. A thin orange line starts from the bottom of the purple circle, extends downwards, then turns left and then down again, ending in a small orange telephone handset icon. The word "Treatment" is written in white text inside the purple circle.

Treatment

For information & support, call

13 11 20

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First published May 2002. This edition August 2018.

© Cancer Council Australia 2018. ISBN 978 1 925651 30 0

Understanding Chemotherapy is reviewed approximately every two years. Check the publication date above to ensure this copy is up to date.

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Acknowledgements

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

We thank the reviewers of this booklet: Dr Prunella Blinman, Medical Oncologist, Concord Cancer Centre, Concord Repatriation General Hospital, and Clinical Senior Lecturer, Sydney Medical School, The University of Sydney, NSW; Gillian Blanchard, Oncology Nurse Practitioner, Calvary Mater Newcastle, and Conjoint Lecturer, School of Nursing and Midwifery, The University of Newcastle, NSW; Julie Bolton, Consumer; Keely Gordon-King, Psychologist, Cancer Council Queensland, QLD; John Jameson, Consumer; Dr Zarnie Lwin, Medical Oncologist, Royal Brisbane and Women's Hospital, and Senior Lecturer, School of Medicine, The University of Queensland, QLD; Caitriona Nienaber, 13 11 20 Consultant, Cancer Council WA; Dr Felicia Roncolato, Medical Oncology Staff Specialist, Macarthur Cancer Therapy Centre, NSW. We also thank the health professionals, consumers and editorial teams who have worked on previous editions of this title.

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

Note to reader

Always consult your doctor about matters that affect your health. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for medical, legal or financial advice. You should obtain independent advice relevant to your specific situation from appropriate professionals, and you may wish to discuss issues raised in this book with them.

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

Cancer Council

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



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About this booklet

This booklet has been prepared to help you understand more about chemotherapy, one of the main treatments for cancer. Chemotherapy treats cancer using a range of drugs.

Many people feel concerned about the side effects of chemotherapy, but most side effects are temporary and they can often be controlled or reduced. The side effects vary depending on the drugs used, and they also vary from one individual to another. We cannot give advice about the best treatment for you, but we hope this information will answer some of your questions and help you think about what to ask your treatment team (see page 59 for a question checklist).

This booklet does not need to be read from cover to cover – just read the parts that are useful to you. Some medical terms that may be unfamiliar are explained in the glossary (see page 60). You may also like to pass this booklet to your family and friends for their information.

How this booklet was developed

This information was developed with help from a range of health professionals and people affected by cancer who have had chemotherapy.

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



**Cancer
Council**
13 11 20

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What is cancer?

Cancer is a disease of the cells. Cells are the body's basic building blocks – they make up tissues and organs. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries.

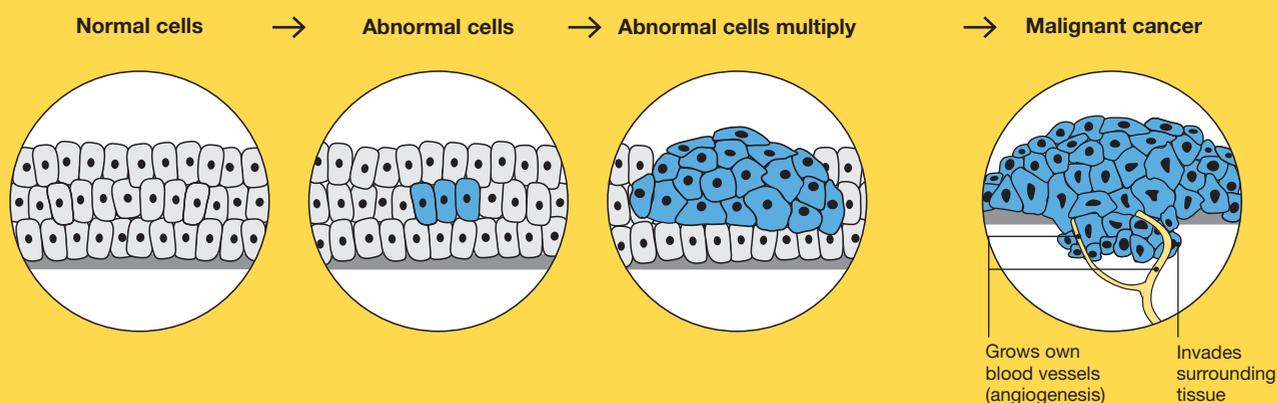
Normally, cells multiply and die in an orderly way, so that each new cell replaces one lost. Sometimes, however, cells become abnormal and keep growing. In solid cancers, such as breast or prostate cancer, the abnormal cells form a mass or lump called a tumour. In some cancers, such as leukaemia, the abnormal cells build up in the blood.

Not all tumours are cancer. Benign tumours tend to grow slowly and usually don't move into other parts of the body or turn into

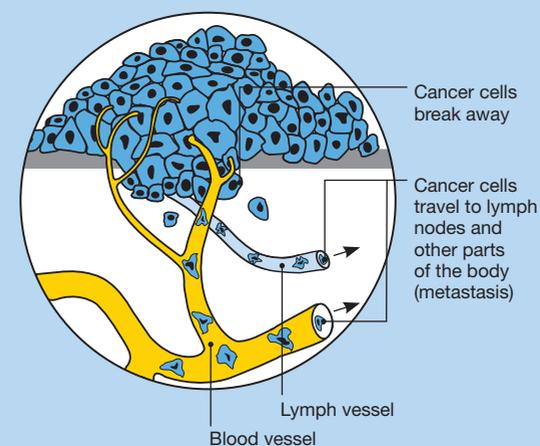
cancer. Cancerous tumours, also known as malignant tumours, have the potential to spread. They may invade nearby tissue, destroying normal cells. The cancer cells can break away and travel through the bloodstream or lymph vessels to other parts of the body.

The cancer that first develops is called the primary cancer. It is considered localised cancer if it has not spread to other parts of the body. If the primary cancer cells grow and form another tumour at a new site, it is called a secondary cancer or metastasis. A metastasis keeps the name of the original cancer. For example, pancreatic cancer that has spread to the liver is called metastatic pancreatic cancer, even though the main symptoms may be coming from the liver.

How cancer starts



How cancer spreads





How is cancer treated?

Most cancers are treated with surgery, chemotherapy and/or radiation therapy (radiotherapy). Other drug treatments, such as hormone therapy, targeted therapy and immunotherapy, can also be used for some types of cancer. The different treatments may be used alone or in combination.

Types of cancer treatments

surgery	An operation to remove cancer or repair a part of the body affected by cancer.
drug therapies	<p>Drugs that are delivered into the bloodstream so the treatment can travel throughout the body. This is called systemic treatment, and includes:</p> <ul style="list-style-type: none"> • chemotherapy – drugs that kill cancer cells or slow their growth (see page 8) • hormone therapy – treatment that blocks the body’s natural hormones. It is used when the cancer is growing in response to hormones • targeted therapy – drugs that attack specific molecules within cells that help cancer grow and spread • immunotherapy – treatment that uses the body’s own immune system to fight cancer.
radiation therapy	The use of targeted radiation to kill or damage cancer cells so they cannot grow, multiply or spread. The radiation is usually in the form of focused x-ray beams. It generally affects only the part of the body where the radiation is targeted.

Your treatments

The treatments you have depend on several factors, including:

- the type of cancer you have
- where it began (primary cancer)
- whether it has spread to other parts of your body (metastatic, called secondary cancer)
- your general health, age and preferences
- what treatments are currently available.

Cancer Council has information about different cancer types and their treatments. Call Cancer Council 13 11 20 for free booklets, or download copies from your local Cancer Council website.

Chemotherapy for children

This booklet is for adults having chemotherapy, although some of the information will also be relevant for children. Ask your doctor for specific information about chemotherapy for children. For age-appropriate support and resources, contact:

- **Camp Quality** – supports children aged 0–13 and their families. Call **1300 662 267** or visit **campquality.org.au**.
- **Redkite** – supports those aged under 24 and their families. Call **1800 733 548** or visit **redkite.org.au**.
- **CanTeen** – supports young people aged 12–25 who have been affected by cancer. Call **1800 226 833** or visit their website at **canteen.org.au**.
- **Cancer Council** – for a copy of *Talking to Kids About Cancer*, call **13 11 20** or download from your local Cancer Council website.



Key questions

Q: What is chemotherapy?

A: Chemotherapy (sometimes just called “chemo”) is the use of drugs to kill or slow the growth of cancer cells. The drugs are called cytotoxics, which means toxic to cells (cyto). Some of these drugs come from natural sources such as plants, while others are completely made in a laboratory.

Q: How does it work?

A: All cells in the body grow by splitting into two cells or dividing. Chemotherapy damages cells that are dividing rapidly. Most chemotherapy drugs enter the bloodstream and travel throughout the body to target rapidly dividing cancer cells in the organs and tissues. This is known as systemic treatment. Sometimes chemotherapy is delivered directly to the cancer. This is known as local chemotherapy.

Q: How is chemotherapy used?

A: You might have treatment with a single chemotherapy drug or a combination of several drugs. There are many different types of chemotherapy drugs, and each type destroys or shrinks cancer cells in a different way.

The chemotherapy drugs you have depend on the type of cancer. This is because different drugs work on different types of cancer. Sometimes chemotherapy is the only treatment needed, but you may also have surgery, radiation therapy or other drug therapies (see page 25 for more details).

Q: Why have chemotherapy?

A: Chemotherapy can be used for different reasons:

To achieve remission or cure – In many cases, chemotherapy causes the signs and symptoms of cancer to reduce or disappear (often referred to as remission or complete response). The treatment may be called curative chemotherapy.

To help other treatments – Chemotherapy is sometimes given either before or after other treatments. If used before (neoadjuvant therapy), the aim is to reduce the cancer so the other treatment is more effective. If chemotherapy is given after the other treatment (adjuvant therapy), the aim is to get rid of any remaining cancer cells. Chemotherapy is often given with radiation therapy to make the radiation therapy more effective.

To control the cancer – Even if chemotherapy cannot achieve remission or complete response (see above), it may be used to control the cancer’s growth and stop it spreading for a period of time. This may be called palliative chemotherapy.

To relieve symptoms – By shrinking a cancer that is causing pain and other symptoms, chemotherapy can improve quality of life. This is also called palliative chemotherapy.

To stop cancer coming back – Chemotherapy might continue for months or years after remission. This is called maintenance chemotherapy, and it may be given with other drug therapies. It aims to prevent or delay the cancer returning.

Q: Why does chemotherapy cause side effects?

A: Chemotherapy works on cells that are dividing rapidly. Cancer cells divide rapidly, as do some healthy cells. These include cells in your blood, mouth, digestive system and hair follicles.

Side effects occur when chemotherapy damages these normal cells. Unlike cancer cells, normal cells can recover, so most side effects are temporary. The drugs used for chemotherapy are constantly being improved to give you the best possible outcomes and to reduce potential side effects. See the *Managing side effects* chapter (pages 32–53) for more information, and talk to your health care team for tips on dealing with side effects.

“When you’ve got to have chemo, it’s quite frightening because you’ve only heard bad things about it. But then I spoke to the oncologist and he explained the benefits.”  Phil

Q: How is chemotherapy given?

A: Chemotherapy is most often given via a vein (intravenously). It is sometimes given in other ways, such as tablets you swallow (oral chemotherapy), as a cream, or as injections into different parts of the body. The choice depends on the type of cancer being treated and the chemotherapy drugs being used. Your treating team will decide which is the most appropriate way to deliver the drugs. For more information, see pages 22–24.

Q: Does chemotherapy hurt?

A: Having a needle inserted for intravenous chemotherapy may feel like having blood taken. If you have a temporary tube (cannula) in your hand or arm, only the initial injection may be uncomfortable. If you have a central venous access device, it should not be painful. Your oncologist will let you know which method is suitable. See pages 22–23 for more details.

Q: Where will I have treatment?

A: Most people have chemotherapy during day visits to a hospital or treatment centre. In some cases, an overnight or extended hospital stay may be needed. People who use a portable pump (see page 23) or have oral chemotherapy can have their treatment at home. Sometimes a visiting nurse can give you intravenous chemotherapy in your home. Your treatment team will discuss which options are available to you.

Q: How much does treatment cost?

A: Chemotherapy drugs are expensive. People do not pay for intravenous chemotherapy received in a public hospital as the cost is covered by the Pharmaceutical Benefits Scheme (PBS). People have to contribute to the cost (co-payment) of oral chemotherapy drugs. You will usually have to pay for any medicines that you take at home to relieve the side effects of chemotherapy (such as anti-nausea medicine). Ask your specialist or treatment centre for a written quote that shows what you will have to pay.

If you have private health insurance and elect to be treated as a private patient, you may have to pay for out-of-pocket expenses and contribute to the cost of the chemotherapy drugs. Check with your doctor and health fund before you start treatment.

Q: How long does treatment last?

A: How often and for how long you have chemotherapy depends on the type of cancer you have and the drugs that are used. You will usually have a number of treatment cycles, and these may be daily, weekly or monthly. See page 20 for more details.

Often people have chemotherapy over 6–12 months, but it's possible to have it for a shorter or longer period. Maintenance chemotherapy (to prevent the cancer coming back) and palliative treatment (to control the cancer or relieve symptoms) may last many months or years.

Q: Can I have chemotherapy during pregnancy?

A: Being diagnosed with cancer during pregnancy is rare. In Australia, about one in 1000 women is affected.¹

While it is possible for some women to have chemotherapy during pregnancy, sometimes chemotherapy and other cancer treatments are delayed until after the baby's birth. Your medical team will discuss all of the available treatment options with you. Their recommendations will be based on the type of cancer you

have, its stage, the other treatment options, and how to avoid harming your developing baby.

Having chemotherapy in the first trimester (12 weeks) may increase the risk of birth defects, but there seems to be a lower risk in the later stages of pregnancy. Studies on babies exposed to chemotherapy in the womb during the second and third trimesters show that chemotherapy did not affect their development.²

However, chemotherapy drugs may affect a developing baby in other ways. For example, chemotherapy may cause premature delivery, and preterm babies often have other health issues, such as respiratory problems.

If you have chemotherapy during pregnancy, you will probably be advised to stop having it at least 3–4 weeks before your delivery date. This is because the side effects of chemotherapy on your blood cells increase your risk of bleeding or getting an infection during the birth. Stopping chemotherapy allows your body time to recover from the side effects. Your doctor can talk in detail about your specific situation and what is best for your health and your unborn baby.



Many pregnant women with cancer feel anxious about the potential impact of treatment on their unborn child. It may be easier to cope if you are well informed about treatments and side effects.

How do I prepare for chemotherapy?

Chemotherapy affects everyone differently, so it can be hard to know exactly how to prepare. However, a number of general issues are worth considering in advance.



Ask about fertility

Some types of chemotherapy can affect your fertility. If you think you may want to have children in future, talk to your oncologist about your options before chemotherapy begins (see page 52).

Pack a chemo bag

A bag for your chemo sessions could include: warm clothing in case you get cold; healthy snacks; lip balm; and something to pass the time, such as books, magazines, crossword puzzles, music with headphones, or a laptop computer or tablet.



Look after yourself

Try to stay as healthy as you can before and during treatment. Eat a nourishing food, drink lots of water, get enough sleep, and balance rest and physical activity. Good nutrition and regular exercise can help reduce some of the side effects of chemotherapy.



Organise help at home

If you have young children, you may need to arrange for someone to look after them during the treatment sessions and possibly afterwards if you become unwell from side effects. Older children may need lifts to and from school and activities. Some support with housework and errands can also ease the load. Ask one friend or family member to coordinate offers of help, or use an online tool such as candoapp.com.au or caringbridge.org.

Discuss your concerns

If you are feeling anxious about the diagnosis and having chemotherapy, talk to a family member or friend, your GP or a member of your health care team, or call **13 11 20** for support. You could also learn relaxation or meditation strategies to cope with anxiety.



Freeze some meals

You may not feel like cooking during the weeks of your chemotherapy treatment. Consider making some meals ahead and freezing them. Sometimes, family and friends will arrange a meal roster.



Talk to your employer

If you are working, talk to your employer about how much time you are likely to need off. It is hard to predict how chemotherapy will affect you, so you could discuss the option of flexible hours or taking some leave.

Check your teeth

It is often a good idea to visit your dentist for a check-up before chemotherapy begins. The dentist can check for any current mouth infections that may cause issues if chemotherapy affects your immune system.



Prepare for side effects

Talk to your treatment team about the likely side effects of the chemotherapy drugs you are having. Ask whether you can take medicine to prevent nausea and vomiting. If you may lose your hair, think about whether you want to cut your hair before treatment starts.



Check other medicines

Make sure your oncologist knows about any other medicines or therapies you are using. Some over-the-counter medicines, home remedies, herbs and vitamins can interfere with the chemotherapy.

Q: Which health professionals will I see?

A: During chemotherapy you will be cared for by a range of health professionals who specialise in different aspects of your treatment. This is called a multidisciplinary team (MDT) and it may include some or all of the professionals listed below.

Note that only some patients see a cancer care coordinator. It is important to maintain or develop a relationship with a general practitioner (GP). This health professional will be involved in your ongoing care, particularly once the cancer treatment finishes.

Health professionals you may see

GP	assists you with treatment decisions and works in partnership with your specialists in providing ongoing care	palliative care specialist* and nurses	work closely with the GP and oncologist to help control symptoms and maintain quality of life
medical oncologist* or haematologist*	treats cancer with drug therapies such as chemotherapy, targeted therapy and immunotherapy (these are known as systemic treatments)	pharmacist	dispenses medicines and gives advice about dosage and side effects
radiation oncologist*	treats cancer by prescribing and overseeing a course of radiation therapy	dietitian	recommends an eating plan to follow while you are in treatment and recovery
surgeon	surgically removes tumours and performs some biopsies; specialist cancer surgeons are called surgical oncologists	social worker	links you to support services and helps you with emotional, practical or financial issues
cancer care coordinator	coordinates your care, liaises with other members of the MDT, and supports you and your family throughout treatment; may also be a clinical nurse consultant (CNC) or clinical nurse specialist (CNS)	occupational therapist, physiotherapist	assist with physical and practical problems, including restoring movement and mobility after treatment and recommending aids and equipment
nurse	administers drugs, including chemotherapy, and provides care, information and support throughout your treatment	psychologist, counsellor	help you manage your emotional response to diagnosis and treatment

* Specialist doctor



Making treatment decisions

Sometimes it is difficult to decide on the type of treatment to have. You may feel that everything is happening too fast, or you might be anxious to get started. Check with your specialist how soon treatment should begin – often it won't affect the success of the treatment to wait a while. Ask them to explain the options, and take as much time as you can before making a decision.

Know your options – Understanding the disease, the available treatments, possible side effects and any extra costs can help you weigh up the options and make a well-informed decision. Check if the specialist is part of a multidisciplinary team (see pages 16–17) and if the treatment centre is the most appropriate one for you – you may be able to have treatment closer to home, or it might be worth travelling to a centre that specialises in a particular treatment.

Record the details – When your doctor first tells you that you have cancer, you may not remember everything you are told. Taking notes or recording the discussion can help. It is a good idea to have a family member or friend go with you to appointments to join in the discussion, take notes or simply listen.

Ask questions – If you are confused or want to check anything, it is important to ask your specialist questions. Try to prepare a list before appointments (see page 59 for suggestions). If you have a lot of questions, you could talk to a cancer care coordinator or nurse.

Consider a second opinion – You may want to get a second opinion from another specialist to confirm or clarify your specialist's recommendations or reassure you that you have explored all of

your options. Specialists are used to people doing this. Your GP or specialist can refer you to another specialist and send your initial results to that person. You can get a second opinion even if you have started treatment or still want to be treated by your first doctor. You might decide you would prefer to be treated by the second specialist.

It's your decision – Adults have the right to accept or refuse any treatment that they are offered. For example, some people with advanced cancer choose treatment that has significant side effects even if it gives only a small benefit for a short period of time. Others decide to focus their treatment on quality of life. You may want to discuss your decision with the treatment team, GP, family and friends.

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

Should I join a clinical trial?

Your doctor or nurse may suggest you take part in a clinical trial.

Doctors run clinical trials to test new or modified treatments and ways of diagnosing disease to see if they are better than current methods. For example, if you join a randomised trial for a new treatment, you will be chosen at random to receive either the best existing treatment or the modified new treatment. Over the years, trials have improved treatments

and led to better outcomes for people diagnosed with cancer.

You may find it helpful to talk to your specialist, clinical trials nurse or GP, or to get a second opinion. If you decide to take part in a clinical trial, you can withdraw at any time. For more information, visit australiancancertrials.gov.au.

► See our *Understanding Clinical Trials and Research* booklet.

Treatment

Your oncologist will record the choice of chemotherapy drugs, the dose and the treatment schedule in a treatment plan. In deciding on which drugs and dose to give you, your oncologist will usually consult clinical guidelines for your cancer type. These guidelines are based on the available evidence. You can ask your oncologist which guidelines they are following.

Most chemotherapy drugs have protocols that set out how much and how often to have a drug – you can find information about protocols for chemotherapy at eviQ Cancer Treatments Online, eviq.org.au. Your specialist may need to tailor the protocols to your individual situation. Tests throughout treatment will monitor your response, and your treatment plan may be adjusted based on the results.

The treatment course

How often and for how long you have chemotherapy depends on the type of cancer you have, the reason for having treatment and the drugs used.

Chemotherapy is commonly given as a period of treatment followed by a break. This is called a cycle. The length of a cycle depends on the chemotherapy drugs being given.

The break between cycles lets your normal cells recover and your body regain its strength. If your body needs more time to recover, your next cycle may be delayed. If you have any concerns about changes to your treatment or any delays, discuss these with your medical oncologist or haematologist.

What to expect when having chemotherapy

This information will apply in most cases, but you may find that things are done slightly differently depending on how you have chemotherapy and where you have treatment.

Before chemotherapy	During chemotherapy
<p>To prepare for chemotherapy and between cycles, you will have a number of tests to help plan treatment:</p> <ul style="list-style-type: none">• weight and height checked to work out the right dose• blood and urine tests to check how well your kidneys and liver are working and the number of blood cells• x-rays and scans to check that you are fit for treatment and see how the tumour is responding to treatment• heart monitoring tests to record your heartbeat (ECG) or heart ultrasound (ECHO) to see if the drugs are affecting your heart• lung function tests to check the effect of some chemotherapy drugs on your lungs.	<p>While receiving chemotherapy you will be:</p> <ul style="list-style-type: none">• seated in a padded chair in a room with other patients; you are usually able to walk around the ward (e.g. if you need to go to the toilet)• given anti-nausea or antiemetic medicine so you don't feel sick• encouraged to drink several glasses of water to help ensure that the chemotherapy drugs don't sit in the kidneys or bladder too long• monitored throughout the session – nurses will talk to you about ways to manage side effects• able to travel to and from chemo by yourself, though it's recommended that someone is with you the first time in case you feel unwell.



Many people are given steroids with their chemotherapy to ease or prevent nausea. Steroids may also be used to manage allergic reactions, to make chemotherapy more effective, or to directly treat the cancer. Steroids may cause indigestion, increase in appetite, irritability or mood swings, difficulty sleeping or increase in blood glucose levels. Some people also experience muscle weakness.

Intravenous (IV) chemotherapy

Chemotherapy is most commonly given through a liquid drip into your vein (intravenously). Depending on the treatment, a single session could take from 20 minutes up to several hours. It will usually be given during day visits to your hospital or treatment centre. Sometimes chemotherapy is given via a portable pump you are able to use at home (see opposite).

Ways of injecting drugs

To prepare you for IV chemotherapy, you will have a narrow tube inserted, usually in a vein in your arm. The treatment team will select the most appropriate device depending on how often you need chemotherapy, how long it will take to give each dose, and how long the device will need to stay in place.

Cannula – A small plastic tube is inserted into a vein in your arm or the back of your hand and taped securely into place. Having a cannula put in can be uncomfortable, but it shouldn't take too long. The cannula is kept in place if you need to stay in hospital for a few days. If you have day treatment every few weeks, the cannula is usually put in and taken out each time you visit.

Central venous access device (CVAD) – A type of thin plastic tube that remains in your vein throughout the course of treatment, often for several weeks or months. Blood for testing can sometimes be taken through this tube. A CVAD shouldn't cause discomfort or pain. Common types of CVADs include:

- central line – inserted into the chest or neck
- Hickman line – inserted into the chest
- PICC (peripherally inserted central catheter) line – inserted into the arm
- port-a-cath (port) – a small device inserted under the skin of the chest or arm.

Portable pump – This device is programmed to give a prescribed amount of chemotherapy continuously over a few days. The pump is usually attached to a central line and is quite small. It can be carried in a bag or belt holster, and can be tucked under a pillow when sleeping. Your hospital or treatment centre will explain how to care for the pump, and they can answer any questions you may have.

Caring for your line or port

Before you go home, a nurse will show you how to look after your line or port to prevent infection or blockage. A nurse may regularly visit you at home to help clean all tubes or lines. It's important to keep the area dry when showering or bathing, and to contact your doctor or nurse immediately if you have pain, discomfort, redness or swelling around the line. If these are signs of an infection, you will be given medicine to help fight the infection, and the device may need to be replaced.

Other ways of having chemotherapy

There are other ways of having chemotherapy, depending on the drugs being used and the type of cancer you have.

Oral chemotherapy – Some people are able to take chemotherapy tablets or capsules at home. Your doctor, nurse or pharmacist will tell you how and when to take them, and how to handle the drugs safely.

Injections – Less commonly, chemotherapy can be injected using a needle into different parts of the body:

- intramuscular – into a muscle, usually in your buttock or thigh
- subcutaneous – just under the skin
- intrathecal – into the fluid around the spine (also known as a lumbar puncture)
- intra-arterial – into an artery
- intraperitoneal – into your abdominal area (peritoneum)
- intrapleural – into the outer lining of the lungs
- intravesical – into the bladder
- intralesional – into the tumour; this method is rare.

Cream – Some skin cancers are treated using a chemotherapy cream applied directly to the skin. This is called topical chemotherapy.

Transarterial chemoembolisation (TACE) – Used for liver cancer or some types of cancer that have spread to the liver, transarterial chemoembolisation involves injecting high doses of chemotherapy directly into the tumour. At the same time, tiny plastic beads or soft, gelatine sponges are also injected to block the blood supply to the tumour (embolisation).

Chemotherapy with other treatments

For some types of cancer, you may be given chemotherapy as part of another treatment, such as a stem cell transplant or radiation therapy, or in combination with other drug therapies.

high-dose chemotherapy	High-dose chemotherapy is given as part of a stem cell transplant for blood cancers, such as leukaemia or lymphoma. It kills off all the cancer cells before the new, healthy blood cells are transplanted. The transplant may occur a day or two later.
chemoradiation	Also called chemoradiotherapy, this is when chemotherapy is given at the same time as the course of radiation. It is used for some cancers, such as bowel cancer, and aims to make the radiation therapy more effective.
hormone therapy	Some cancers, such as breast and prostate cancer, can grow in response to hormones. Drugs that block these hormones may be given as tablets or injections. Used in combination with chemotherapy.
targeted therapy	Often used in combination with chemotherapy, targeted therapy drugs may be given intravenously or as tablets. ▶ See our <i>Understanding Targeted Therapy</i> fact sheet.
immunotherapy	May be given as tablets or injections, alongside chemotherapy. ▶ See our <i>Understanding Immunotherapy</i> fact sheet.

Waiting for chemotherapy

When you have chemotherapy, you may spend a lot of time waiting for health professionals, for blood tests, for test results, for your drugs to be prepared and for the drugs to be given. There are sometimes additional delays because of necessary safety checks, emergencies or the workload of the treatment centre. Many treatment centres will provide biscuits and water, tea and coffee, but it's a good idea to bring your own water bottle and snacks in case of long delays.

To help pass the time, you may want to:

- read a book or magazine, or listen to music or a podcast, such as *The Thing About Cancer*
- complete a crossword or other puzzle
- chat with a companion
- write or draw in a journal
- meditate or practise relaxation techniques
- use a laptop, tablet or other electronic device – check with the nurses whether this is okay and if power points are available.

At first, you may feel uncomfortable being around people who are sick because of cancer or their treatment. You may not identify with them. However, many people gain support from others who are receiving chemotherapy at the same time.

“ I became good friends with a lady who began chemotherapy on the same day as me. We ended up going walking several times a week for 18 months. The companionship was a great support. ” Tania



If you smoke, try to quit or cut down before chemotherapy starts as smoking may affect how well the treatment works and make side effects worse. Quitting can be difficult, especially if you're feeling anxious about the cancer diagnosis and treatment. For support and advice, talk to your doctor, call the Quitline on **13 7848**, download the My QuitBuddy app or visit quitnow.gov.au.

Safety precautions

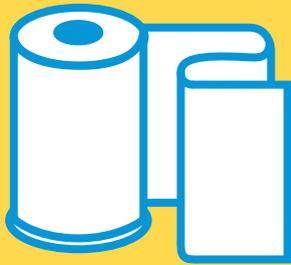
Chemotherapy is strong medicine, so it is safest for people without cancer to avoid direct contact with the drugs. That's why oncology nurses and doctors wear gloves, goggles, gowns and, sometimes, masks. When the treatment session is over, these items are disposed of in special bags or bins.

After each chemotherapy session, the drugs may remain in your body for up to a week. This depends on the type of drugs used. The drugs are then released into urine, faeces and vomit. They could also be passed to other body fluids such as saliva, sweat, semen or vaginal discharge, and breast milk.

Some people having chemotherapy worry about the safety of family and friends. There is little risk to visitors, including children, babies and pregnant women, because they aren't likely to come into contact with any chemotherapy drugs or body fluids. The safety measures listed on the next two pages are recommended for family or friends who are providing care or have other close contact during the recovery period at home. If you have questions, talk to your treatment team or call Cancer Council 13 11 20.

Chemotherapy safety in the home

Follow these safety guidelines to reduce exposure to chemotherapy drugs at home, both for you and your family and friends. Safety precautions can vary depending on the drugs you receive, so ask your treatment team about your individual situation.



Clean up spills

Keep a supply of cleaning cloths, paper towels and disposable waterproof gloves handy. If any body fluids (during the week after a treatment session) or chemotherapy drugs spill onto household surfaces, put on a pair of waterproof gloves, soak up the spill with paper towels, clean around the area with a disposable cloth and soapy water, and rinse the area with water. Seal used gloves, cloths and paper towels in a plastic bag before putting them in the bin.

Use a plastic bucket

Vomit into a plastic bowl or bucket (or a plastic bag with no holes). Don't use the bowl or bucket for anything else, and throw it out after your final chemotherapy session.



Take care going to the toilet

For a week after a treatment session, sit down to use the toilet. Put the lid down before flushing to avoid splashing.

Wear disposable gloves

During the week after a treatment session, wear disposable waterproof gloves when handling clothing or bedsheets soiled with vomit or other body fluids. Seal the gloves in a plastic bag and discard after use.



Keep tablets whole

Don't crush, chew or cut chemotherapy tablets. If you can't swallow a tablet whole, ask your oncologist or pharmacist whether the drugs come in other preparations (i.e. liquid).



Handle laundry carefully

Wash clothing or other items soiled with body fluids separately. Use the longest washing machine cycle (hot or cold water can be used). Line dry the items.



Put medicines in a safe place

Store all tablets, capsules or injections as directed by your oncologist or pharmacist – they often need special storage to keep them effective and safe. Keep them out of reach of children, and do not store them in a pill organiser with other medicines.

Use protection

Use a condom or a female condom if having any type of sex after a chemotherapy session. Your doctor or nurse can give you more details about how long you need to use protection.



Pregnancy and breastfeeding

Avoid pregnancy while having chemotherapy (see page 51). If you have a baby, you will not be able to breastfeed during your course of chemotherapy.

Is the treatment working?

You might wonder whether experiencing side effects is a sign that the chemotherapy is working. However, side effects usually do not indicate how successful the chemotherapy is going to be.

Your doctor may do physical examinations and other tests to see if the cancer has shrunk or disappeared after chemotherapy. This is called the treatment response and it helps your doctor decide whether to continue or change the chemotherapy plan.

If tests show that the cancer has shrunk and is unable to be detected, this may be called remission or complete response, which means there is no evidence of active cancer. Depending on the guidelines for the type of cancer you have, this may mean chemotherapy can stop or it may continue for a period of time. Once you've completed the course of chemotherapy, your doctor will monitor you for several months or years (see page 55). This is because cancer can sometimes come back in the same place or grow in another part of the body.



Key points about chemotherapy

What it is

- Chemotherapy is the use of drugs that kill or slow the growth of cancer cells.
- You may have one drug or a combination of drugs depending on the cancer type.

How chemotherapy is given

- Most commonly given via a thin tube into a vein (intravenously).
- Chemotherapy is sometimes given by mouth as tablets or capsules (orally).
- For some types of cancer, chemotherapy is given in other ways, e.g. cream for skin cancer, injections for liver cancer.
- A medical oncologist or haematologist prescribes the course of chemotherapy. Other health professionals also provide care as part of a multidisciplinary team.

Safety of chemotherapy

- It is safest for people without cancer to avoid direct contact with chemotherapy drugs, so nurses and doctors wear protective clothing when giving chemotherapy. However, there is little risk to visitors during and after your chemotherapy treatment.
- Your treatment team will advise you about taking precautions at home so your family members don't come into contact with chemotherapy drugs or your body fluids, such as urine or vomit.
- Your family and friends should also handle chemotherapy drugs with care.



Managing side effects

Chemotherapy affects all cells that grow and divide quickly in the body. This includes cancer cells and normal cells, such as the new blood cells in the bone marrow or the cells in the mouth, stomach, skin, hair and reproductive organs. When chemotherapy damages normal cells, this causes side effects.

Whether or not you experience side effects, and how severe they are, depends on the type and dose of drugs you are given and your reaction from one treatment cycle to the next. Most side effects are short-term and can be managed. They tend to gradually improve once treatment stops and the normal, healthy cells recover. Sometimes, chemotherapy causes long-term side effects that don't go away. These may include damage to your heart, lungs, nerve endings, kidneys, or reproductive organs.

You may worry about the side effects of chemotherapy. If you feel upset or anxious about how long treatment is taking or the impact of side effects, let your doctor or nurse know. The drugs used for chemotherapy are constantly being improved to give you the best possible results and to reduce potential side effects. This chapter explains ways to manage the discomfort side effects may cause.

Preparing for side effects

Some people have no side effects, others experience a range. If you have side effects, they will usually start during the first few weeks of treatment and may become more intense with each treatment cycle. Before treatment begins, your doctor or nurse will discuss the side effects to watch out for or report, how to help prevent or manage them, and who to contact after hours if you need help.



If side effects change your appearance and self-esteem, consider registering for a free Look Good Feel Better workshop. For more details and to book, call **1800 650 960** or visit lgfb.org.au. You may also find it helpful to speak with a psychologist or counsellor, who can provide emotional support.

Recording side effects

It can be useful to keep a record of your chemotherapy treatment in one place. This will help you recall details about when you experienced side effects, how long they lasted, and what helped to make them better. Some people use a notebook or a diary, while others prefer to use a smartphone or tablet.

Share the information you record with your doctors and nurses. They will be able to suggest ways to manage the side effects or, if appropriate, they may adjust your treatment.

Trying complementary therapies

Complementary therapies are sometimes used with conventional medical treatments. They may offer physical, emotional and spiritual support, help manage side effects, and improve quality of life.

Some therapies have been proven to be safe and effective in scientific studies. For example, therapies such as meditation, relaxation, massage and counselling can reduce anxiety, and acupuncture can reduce chemotherapy-induced nausea and fatigue. These therapies are part of guidelines for complementary therapies and breast cancer.

It is important to talk to your doctors about any complementary therapies you are using or thinking about trying, as some could interfere with your treatment or make side effects worse. Complementary therapies are different to alternative therapies, which are used instead of conventional medical treatments. These are unlikely to be scientifically tested and may prevent successful treatment of the cancer. Cancer Council does not recommend the use of alternative therapies.

➤ See our *Understanding Complementary Therapies* booklet.

Feeling tired and lacking energy

Feeling tired and lacking energy (fatigue) is the most common side effect of chemotherapy. Fatigue can include feeling exhausted, drowsy, confused or impatient. You may have a heavy feeling in your limbs, get worn out quickly, or find it difficult to do daily activities.

Fatigue can appear suddenly, and rest may not relieve it. You might still feel tired for weeks or months after a treatment cycle ends.

While fatigue is a common side effect of chemotherapy, it can also be a symptom of depression (see page 54). For more information on depression, visit beyondblue.org.au and talk to your cancer care team.

“ I had no idea that I would still be feeling tired five months after finishing treatment. I didn't know how to make it better and I was scared that's how it would be: that I wouldn't go back to normal, that I would never go back to having energy again. ” Judy

Tips for managing fatigue

- Plan activities for the time of day when you tend to feel most energetic.
- Allow your body to recover by taking regular breaks.
- Make time for regular exercise. Light to moderate exercise can reduce treatment-related fatigue and improve mood. Talk to your health care team about suitable activities for you. You can also call **13 11 20** for a free copy of our *Exercise for People Living with Cancer* booklet, or download a digital version from your local Cancer Council website.
- Ask for, and accept, offers of support from family, friends and neighbours. They can help with shopping, driving, housework or gardening.
- If you have children, ask trusted family and friends to look after them during your chemotherapy sessions and to be on call in case you become unwell afterwards.
- Find ways to manage anxiety and/or trouble sleeping as these can affect fatigue. Relaxation or meditation exercises may help improve your sleep or give you more energy. Call **13 11 20** and check whether your local Cancer Council can provide CDs, or listen to *The Thing About Cancer* podcast episodes on fatigue and sleep.
- Consider trying acupuncture – some studies suggest this may help reduce physical tiredness after chemotherapy.
- See the next two pages for tips on dealing with exhaustion caused by a poor appetite, nausea and/or vomiting.
- Check with your doctor whether your fatigue is related to low levels of red blood cells (anaemia). Anaemia can be treated (see page 45).
- Discuss the impact of the treatment with your employer. Some workplaces may allow you to work flexibly during or after chemotherapy. Options include taking a few weeks off, reducing your hours or working from home.

Appetite changes, nausea or vomiting

It is common for your appetite to change when you are going through chemotherapy. The drugs may also temporarily change how food tastes. Sometimes you may not feel hungry or you may prefer different types of food.

Chemotherapy can make you feel sick (nauseated) or cause you to vomit. Not everyone feels sick during or after chemotherapy, but if nausea affects you, it will usually start a few hours after treatment. Nausea may last for many hours and be accompanied by vomiting or retching. Sometimes nausea lasts for days after treatment.

Often the best way to manage nausea is to prevent it from starting. Anti-nausea (antiemetic) medicine helps most people, but finding the right one can take time. If nausea or vomiting continue after using the prescribed medicine, let your nurse or doctor know so that another medicine can be tried. Steroids may also be used to manage nausea (see page 22).

Being unable to keep liquids down because of vomiting can cause you to become dehydrated. Signs of dehydration include a dry mouth and skin, dark urine, dizziness and confusion. It is not safe to be left alone if you are vomiting a lot, as the confusion may make it difficult to realise you have become seriously dehydrated.

“Once I started chemotherapy, I went off my food. My mouth felt very dry, which made food taste unappetising. Adding extra sauce helped.”  Helen



Tips for coping with nausea and changed appetite

Managing appetite loss

- Eat what you feel like, when you feel like it. Have frequent snacks instead of large meals.
- Try to eat extra on days when you have an appetite.
- Avoid strong odours and cooking smells that may put you off eating. It might help to prepare meals ahead and freeze them for days you don't feel like cooking.
- If the taste of certain foods has changed, don't force yourself to eat them. Your sense of taste should return to normal after treatment ends.
- If you don't feel like eating solid foods, try enriching your drinks with powdered milk, yoghurt, eggs or honey.
- Don't use nutritional supplements without your doctor's advice, as some could interfere with treatment.
- Ask a dietitian for advice on the best eating plan during treatment and recovery.

Managing nausea

- Eat a light, bland meal before your treatment (e.g. soup with dry biscuits, crackers or toast).
- Keep sipping fluids so that you don't get dehydrated. If you aren't able to keep fluids down, contact your doctor or hospital immediately. They may be able to treat the vomiting, or you may need to have fluids through an intravenous drip in hospital.
- Sip fluids throughout the day. Sucking on ice cubes, iceblocks or jellies can also increase your fluid intake. If water tastes unpleasant, flavour it with ginger cordial or syrup.
- If your stomach is upset, try drinking fizzy drinks such as soda water or dry ginger ale.
- If you wake up feeling sick, eat a dry biscuit or slice of toast rather than skipping food.
- Listen to the *The Thing About Cancer* podcast episode on appetite loss and nausea.

Constipation or diarrhoea

Some chemotherapy drugs, pain medicines and anti-nausea drugs can cause constipation or diarrhoea. Tell your doctor or nurse if your bowel habits have changed.



Tips for managing bowel changes

Constipation	Diarrhoea
<ul style="list-style-type: none">• Eat more high-fibre foods, such as wholegrain bread and pasta, bran, fruits and vegetables, nuts and legumes (e.g. baked beans or lentils).• Drink plenty of fluids, both warm and cold, to help loosen the bowels. Prune, apple or pear juice can work well.• Do some light exercise, such as walking.• Ask your doctor about using a laxative, stool softener and/or fibre supplement.• Avoid enemas or suppositories as they may cause infection.• Let your treatment team know if you have constipation for more than a couple of days. They will be able to help.	<ul style="list-style-type: none">• Choose bland foods such as clear broth or boiled rice. Avoid spicy foods, wholegrain products, fatty or fried foods, rich sauces, and raw fruits or vegetables with skins or seeds.• Limit alcohol, fruit juice, soft drinks, strong tea or coffee, and dairy products, as these stimulate the bowel.• Drink water to help replace fluids lost through diarrhoea.• Talk to your cancer care team – they may change the treatment or suggest other solutions, such as using over-the-counter medicines.• If diarrhoea is severe, let your cancer care team know. It can cause dehydration and you may need to go to hospital.



Watery eyes can be a symptom of a blocked tear duct. This can be caused by some chemotherapy drugs. Regularly massaging the area and using eye drops can help clear blockages. Let your cancer care team know if this issue is ongoing.

Hair loss

Many people having chemotherapy worry about hair loss (alopecia). Whether or not you lose your hair will depend on the drugs you are prescribed. Some people lose all their hair quickly and others lose it after several treatments, while others may lose only a little hair or none at all. Although losing head hair is most common, you may find your eyebrows and eyelashes fall out, and you may lose hair from your underarms, legs, chest and pubic region.

When hair loss does occur, it usually starts 2–3 weeks after the first treatment. Before and while your hair is falling out, your scalp may feel hot, itchy, tender or tingly. Some people find that the skin on their head is extra sensitive, and they may develop pimples on their scalp. After chemotherapy ends, it takes 4–12 months to grow back a full head of hair. When your hair first grows back, it may be a different colour or curly (even if you have always had straight hair). In time, your hair usually returns to its original condition.

Coping with hair loss

Many people find losing their hair difficult. Your hair may help form part of your sense of self – its loss can affect your self-confidence and make you feel sad or vulnerable. For many people, it's a public sign of the cancer diagnosis. Talking to your treatment team may help.

Scalp cooling

Some people may be able to reduce or prevent hair loss by using a “cold cap”. This works by temporarily reducing the blood flow and the amount of chemotherapy drug that reaches the scalp. A cap is worn on the head and attached via a hose to a cooling unit, which fills the cap with cold liquid. It is worn while the chemotherapy is delivered.

The cold cap can only be used with certain drugs and types of cancer, and doesn't always prevent hair loss. Check with your doctor or nurse whether a cold cap would be an option for you and whether it is available at your treatment centre.



Karen's story

I'd been feeling unwell – eating made me feel nauseous and I couldn't stand to have anything tight around my stomach. My GP booked me in for some scans and then I was referred to an oncologist and I had a biopsy. After that, the diagnosis of non-Hodgkin lymphoma was confirmed.

I received the standard chemotherapy drugs for the first few months of treatment, and then I took part in a clinical trial.

During the week I had treatment, I would feel okay as the nurses would give me medicine. The next week, I would get side effects like diarrhoea, vomiting and constipation. I took ginger to help with the nausea, and I tried to live my normal life whenever I felt well enough.

I had good support from work, my family and friends, and the hospital staff were brilliant. I still have regular check-ups and I'm back to living my usual active life.



Tips for managing hair loss

- Keep your hair and scalp very clean. Use a mild shampoo like baby shampoo. If you want to use lotion on your head, use sorbolene. Check with your nurse before using any other hair or skin care products.
- Comb or brush your hair gently using a large comb or a hairbrush with soft bristles.
- Explain to family and friends, especially children, that the chemotherapy may make your hair fall out.
- Cut your hair, especially if it is long, before it falls out. Some people say this gives them a sense of control.
- Wear a light cotton turban or beanie to bed if you are cold at night.
- Use a cotton, polyester or satin pillowcase, as nylon can irritate your scalp.
- Talk to your hairdresser about making your hair look as good as possible even if it is thin or patchy. If you want to dye your hair during or for about six months after chemotherapy, it is best to use vegetable-based, non-chemical dyes.
- If your eyelashes fall out, wear sunglasses outside to protect your eyes from dust and sun.
- Wear a wig, hat, turban or scarf, or go bare-headed – whatever feels best to you. If you prefer to leave your head bare, protect it against sunburn and the cold.
- Consider choosing a wig before chemotherapy starts. Call Cancer Council **13 11 20** for assistance in finding a wig library or shop.
- Consider registering for a Look Good Feel Better workshop, where you can try on wigs and other head wear and learn new make-up techniques. Call **1800 650 960** or visit lgfb.org.au.
- Read Cancer Council's *Hair Loss* fact sheet available from your local Cancer Council website, or call **13 11 20** for more information.

Mouth sores

Some chemotherapy drugs can cause mouth sores, such as ulcers, or infections. This is more likely if you have had or are having radiation therapy to the head, neck or chest, or if you have dental or gum problems.

If you notice any sores, ulcers or thickened saliva, or if you find it difficult to swallow, tell your doctor.



Tips for mouth care

- Discuss any dental issues with your oncologist before seeing the dentist. If you need any dental work, tell your dentist you're having chemotherapy.
- Use a soft toothbrush to clean your teeth twice a day.
- Rinse your mouth four times a day with 1 tsp bicarbonate of soda or salt in a glass of warm water. Avoid mouthwashes containing alcohol.
- Try to prevent mouth ulcers by sucking on ice during chemotherapy sessions.
- Sip fluids, especially water, and eat moist foods such as casseroles or soups if you have a dry mouth. Moisten foods with gravy or sauce.
- Soothe tender gums or mouth with plain yoghurt.
- Blend foods to make them easier to eat. Try smoothies made of fruit and yoghurt.
- Avoid smoking and alcoholic drinks, as well as very hot foods and spicy, acidic or coarse foods (e.g. nuts or grains). These can all aggravate mouth sores.
- Read the *Mouth Health and Cancer Treatment* fact sheet, available from your local Cancer Council website, or call **13 11 20** for information.

Skin and nail changes

Some chemotherapy drugs may cause your skin to peel, darken or become dry and itchy. During treatment and for several months afterwards, your skin is likely to be more sensitive to the sun.

Some people find their nails also change and become darker than usual, or develop ridges or white lines across them. Your nails may also become brittle and dry. These changes usually grow out.



Tips for looking after your skin and nails

- Use a moisturising soap or sorbolene cream as a soap replacement. After showering, gently pat your skin dry with a towel rather than rubbing it.
- Use a moisturising lotion or cream containing the ingredient urea to help with the dryness.
- Wear loose, non-restricting clothing. Choose cotton fabric instead of rough wool or synthetic fibres.
- Wash your clothing in mild detergent for people with sensitive skin.
- Stop shaving or waxing until your skin is healed.
- Protect your skin from the sun when UV levels are 3 or above. Wear high-protection sunscreen (SPF 50+), a broad-brimmed hat, protective clothing and sunglasses, and try to stay in the shade. This advice applies to everyone, but is especially important when having chemotherapy.
- If your skin becomes red or sore in the area where the intravenous device went in, let your doctor or nurse know immediately.
- Avoid chlorinated swimming pools as the water can make skin changes worse.

Thinking and memory changes

Some people say they have difficulty concentrating, focusing and remembering things after they have had chemotherapy. This is called cancer-related cognitive impairment or, sometimes, “chemo brain” or “cancer fog”. Thinking and memory changes may be caused by treatment or medicines, fatigue and sleep problems, or emotional concerns, such as stress or depression. These problems usually improve with time, although some people experience issues for years.

Tell your doctor about any thinking and memory changes you are having, and if this issue is affecting your day-to-day life or your return to work.



Tips for managing cognitive changes

- Use a calendar to keep track of tasks, appointments, social commitments, birthdays, etc.
- Write down anything you need to remember, e.g. to-do items, where you parked the car, when to take medicine.
- Get plenty of sleep. Deep sleep is important for memory and concentration.
- Do light exercise every day to help you feel more alert and sleep better.
- Learn something new, e.g. take up a new hobby or do crosswords or puzzles.
- Discuss these issues with your partner, family or workplace, and ask for their support or assistance.
- Read the *Understanding Changes in Thinking and Memory* fact sheet, available from your local Cancer Council website. You can also listen to *The Thing About Cancer* podcast episode on brain fog.

How chemotherapy affects the blood

Blood cells are made in the bone marrow, which is the spongy part in the centre of the bones. The bone marrow makes three main types of blood cells, which have specific functions:

- **red blood cells** – carry oxygen around the body
- **white blood cells** – fight infection
- **platelets** – help blood to clot and prevent bruising.

Because the new blood cells are rapidly dividing, they can be damaged by chemotherapy, and the number of blood cells (your blood count) will be reduced. Low numbers of blood cells may cause anaemia, infections or bleeding problems.

You will have blood tests at the beginning of treatment and before each chemotherapy cycle to check that your blood count has returned to normal before you have chemotherapy.

Anaemia

If your red blood cell count drops, a reduced amount of oxygen circulates through your body. This can cause anaemia, which can make you feel tired, lethargic, dizzy or breathless. The tips for coping with fatigue on pages 34–35 may be helpful. To minimise dizziness, take your time when you get up from sitting or lying down.

Your treatment team will monitor your red blood cell levels. Let them know if you experience any symptoms of anaemia while having chemotherapy. If the levels of red blood cells drop too low, you may need a blood transfusion to build them up again.

Infections

If white blood cell numbers drop during chemotherapy, it can lower your immunity. This makes you more likely to get infections and less able to fight any infections that do occur. Your doctor may recommend antibiotics as a precaution against infection.

Many types of white blood cells make up the total white cell count. A type of white blood cell known as a neutrophil protects you against infection by destroying harmful bacteria and yeasts that enter the body. During chemotherapy, some people get low levels of neutrophils. This is known as neutropenia.

If you have neutropenia, you may be given an injection of growth factor drugs called granulocyte-colony stimulating factor (G-CSF) after chemotherapy to encourage the bone marrow to make more white blood cells. Your doctor or nurse will speak to you about possible side effects. Some people may experience bone pain or tenderness at the injection site, or show signs of an allergic reaction.

During chemotherapy treatment, even a minor infection could become serious quickly. See opposite for when you need to contact your doctor urgently.

“After chemotherapy I became very susceptible to infections. A small scrape can quickly become serious. But when I feel like an infection is coming on, I’ve learnt to see my doctor straightaway.”  Brigita

Taking care with infections during chemotherapy

Reduce your risk

To prevent the spread of infection:

- check with your doctor about having the flu vaccine
- ask people close to you to consider having a flu shot
- ask family and friends with a cold, flu or other contagious infection (e.g. chickenpox, measles or a cold sore) to wait until they feel well before visiting
- as far as practical, avoid close contact with people you live with if they are unwell
- try to avoid crowded places, such as shopping centres or public transport in peak hour
- wash your hands with soap and water before preparing food and eating, and after using the toilet
- prepare and store food properly to avoid foodborne illness and food poisoning
- eat freshly cooked foods; avoid raw fish, seafood, meat, eggs and soft cheeses; and wash fruits and vegetables well before eating.

When to seek medical help

Contact your doctor or go to the nearest hospital emergency department immediately if you experience one or more of the following symptoms:

- a temperature of 38°C or higher
- chills or shivering
- sweating, especially at night
- burning or stinging feeling when urinating
- a severe cough or sore throat
- shortness of breath
- vomiting that lasts more than a few hours
- severe abdominal pain, constipation or diarrhoea
- unusual bleeding or bruising, such as nosebleeds, blood in your urine or black bowel motions
- prolonged faintness or dizziness and a rapid heartbeat
- any sudden deterioration in your health.

Bleeding problems

Platelets are the blood cells that help the blood to clot. A low level of platelets (thrombocytopenia) can cause problems with bleeding. You may bleed for longer than normal after minor cuts or scrapes, have nosebleeds or bleeding gums, or bruise easily.

Your treatment team will monitor your platelet levels. If chemotherapy causes thrombocytopenia, you may need a platelet transfusion. Ask your oncologist to explain the risks and benefits of platelet transfusion.

Contact your treatment team or call 000 if you have any persistent bleeding, such as a nosebleed that doesn't stop within 30 minutes.

Nerve and muscle effects

Some drugs can cause tingling (“pins and needles”), numbness or pain in your fingers and/or toes, and muscle weakness in your legs. This is called peripheral neuropathy. It is caused by damage to the nerves that send signals between the central nervous system and the arms and legs.

For many people, peripheral neuropathy is a short-term issue, but for others, it can last a long time or even be permanent. If you experience numbness and tingling, tell your doctor or nurse before your next treatment. Your treatment may need to be changed or the problem carefully monitored.



Tips for when you have a low platelet count

- Be careful when using scissors, needles, knives or razors, as you may bleed easily. Small cuts or nicks can also harbour germs where an infection can start.
- Use an electric razor when shaving to reduce the chance of nicking yourself.
- Wear thick gloves when gardening to avoid injury. (The gloves will also prevent infection from soil, which contains bacteria.)
- Use a toothbrush with soft bristles to avoid irritating your gums.
- Wear comfortable, well-fitting shoes indoors and outdoors to avoid cuts and scrapes on your feet.
- Blow your nose with care.
- If you bleed, apply pressure for about 10 minutes and bandage as needed.
- If you have problems with bleeding, talk to your doctor.



Tips for managing numb hands or feet

- Take care when moving around – you may be more prone to trip and fall if your feet are numb or your legs are weak.
- Use gloves and warm socks to keep your hands and feet warm, or soak your hands and feet in warm water to relieve symptoms.
- Use your elbow to check water temperature so you don't scald yourself.
- Talk to an occupational therapist from your treatment team about aids that may help, e.g. posts to raise the sheets off your feet if they're irritated by the weight of the sheets.
- Some treatment centres offer ice mitts to help reduce peripheral neuropathy. If you are interested in trying these, ask your treatment centre if they are available and how much they cost.
- If your symptoms are severe, talk to your doctor about medicines that may offer relief.

Changes in hearing

Some chemotherapy drugs can affect your hearing. Your doctor may recommend that you have a hearing test before you start treatment, and this may be repeated before each cycle of chemo. You may be at risk of losing the ability to hear high-pitched sounds. Sometimes, chemotherapy also causes a continuous ringing noise in the ears known as tinnitus. While these changes are usually temporary, let your doctor know if you notice any change in your hearing.

Sex and fertility

Chemotherapy can have an impact on your desire (libido) or ability to have sex. It may also affect sexual organs and functioning in men and women. This can affect your ability to have children (fertility).

Changes in sexuality

A range of issues can cause people to lose interest in sex while they're having treatment. Aside from feeling tired and unwell, you may feel less confident about who you are and what you can do. There may also be a physical reason for not being able or interested in having sex, e.g. vaginal dryness or erection difficulties. Changes in appearance can also affect feelings of self-esteem and, in turn, sexuality.

If you have a partner, it may be helpful for them to understand the reasons why your libido has changed and to know that people can have a fulfilling sex life after cancer, but it often takes time. Some partners may also feel concerned about having sex – they might fear injuring the person with cancer or feel uncomfortable with the changes in their partner.

If you have sex after receiving chemotherapy, follow the contraception recommendations outlined below.

Sexual intercourse may not always be possible, but closeness and sharing can still be a part of your relationship. Talk about how you're feeling with your partner and take time to adapt to any changes. Try to see yourself as a whole person (body, mind and personality) instead of focusing only on what has changed. If you're worried about the changes to your relationships or sexual functioning, you may find talking to a psychologist or counsellor helpful.

- ▶ See our *Sexuality, Intimacy and Cancer* booklet, and listen to *The Thing About Cancer* podcast episode on sex and cancer.

Using contraception

Your doctor may talk to you about using contraception during and after chemotherapy. Although chemotherapy often affects fertility, this doesn't mean it rules out pregnancy. Some women can still become pregnant while having chemotherapy, and a man having chemotherapy could still make his partner pregnant.

Chemotherapy drugs can harm an unborn baby (see pages 12–13), so women should plan to avoid becoming pregnant during chemotherapy treatment, and men should not father a child. If you or your partner become pregnant, talk to your specialist immediately. The type of birth control you choose will depend on what you and your partner are comfortable using. Some people use barrier contraception such as a condom or female condom, which provides protection against any chemotherapy drugs that may be present in their body fluids.

Changes in fertility

If you want to have children in the future, talk to your doctor about how chemotherapy might affect you and what options are available. Women may be able to store eggs (ova) or embryos, and men may be able to store sperm for use at a later date. This needs to be done before chemotherapy starts and requires careful consideration.

➤ See Cancer Council's *Fertility and Cancer* booklet.

Effects of chemotherapy on women – Chemotherapy can reduce the levels of hormones produced by the ovaries. For some women, this causes periods to become irregular during chemotherapy but they return to normal after treatment. For other women, chemotherapy may cause periods to stop completely (menopause). After menopause, women can't conceive children. Signs of menopause include hot flushes, sweating (especially at night), and dry skin. Menopause – particularly when it occurs in women under 40 – may, in the long term, cause bones to become weaker and break more easily. This is called osteoporosis. Talk to your doctor about ways to manage menopausal symptoms.

Effects of chemotherapy on men – Chemotherapy drugs may lower the number of sperm produced and reduce their ability to move. This can sometimes cause infertility, which may be temporary or permanent. The ability to have and keep an erection may also be affected, but this is usually temporary. If the problem is ongoing, talk to your doctor.



Key points about side effects

Why side effects occur

Many people experience side effects from chemotherapy. Side effects are caused when the chemotherapy damages rapidly dividing healthy cells.

Common side effects

- Chemotherapy can cause fatigue, loss of appetite, nausea, bowel issues such as constipation or diarrhoea, hair loss, mouth sores, skin and nail problems.
- You may have trouble concentrating or remembering things. There can also be nerve and muscle effects and hearing changes.
- You will be at increased risk of infections. This is because chemotherapy can reduce your levels of white blood cells, which are necessary for fighting infections.
- You may have sexuality and fertility problems, such as reduced sexual desire or loss of fertility. You might be able to store eggs (ova), embryos or sperm for use at a later date. Talk to your doctor about these issues.
- Most side effects are temporary and gradually improve after you have finished treatment.

Managing side effects

- Your doctor or nurse will advise you on how to cope with any side effects. You may be prescribed medicine or given suggestions for eating, drinking and looking after yourself.
- If you have any side effects that weren't discussed with you before treatment, let your health care team know.



Life after treatment

For most people, the cancer experience doesn't end on the last day of chemotherapy. 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.

Some people say that they feel pressure to return to "normal life". 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.

Cancer Council 13 11 20 can help you connect with other people who have had cancer, and provide you with information about the emotional and practical aspects of living well after cancer.

► See our *Living Well After Cancer* booklet.

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 among people who have had cancer.

Talk to your GP, as counselling or medication – even for a short time – may help. Some people can get a Medicare rebate for

sessions with a psychologist. Ask your doctor if you are eligible. Cancer Council may also run a counselling program in your area.

For information about coping with depression and anxiety, call **beyondblue** on **1300 22 4636** or visit **beyondblue.org.au**. For 24-hour crisis support, call Lifeline **13 11 14** or visit **lifeline.org.au**.

Follow-up appointments

After chemotherapy ends, you will have regular appointments with your oncologist or haematologist to monitor your health, manage any long-term side effects, and check that the cancer hasn't come back or spread. These will become less frequent over time. During these check-ups, you will usually have a physical examination and you may have blood tests, x-rays or scans. You will also be able to discuss how you're feeling and mention any concerns you may have.

You may also have regular check-ups with other specialists who have been involved in your treatment. Ask your treatment team whether you can space out these appointments.

When a follow-up appointment or test is approaching, many people find that they think more about the cancer and may feel anxious. Talk to your treatment team or call Cancer Council 13 11 20 if you are finding it hard to manage this anxiety.

Check-ups will become less frequent if you have no further problems. Between follow-up appointments, let your doctor know immediately of any symptoms or health problems.

“ You never get back to the normal you knew before you had cancer. It's a series of evolutions – evolving as a different person. ” Julie

Support from Cancer Council

Cancer Council offers a range of services to support people affected by cancer, their families and friends. Services may vary depending on where you live.

Cancer Council 13 11 20

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



Information resources

Cancer Council produces booklets and fact sheets on over 25 types of cancer, as well as treatments, emotional and practical issues, and recovery. Call **13 11 20** or visit your local Cancer Council website (see back cover).

Practical help

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



Legal and financial support

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

Peer support services

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



Useful websites

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

Australian

Cancer Council Australia	cancer.org.au
Cancer Australia	canceraustralia.gov.au
Cancer Council Online Community	cancercouncil.com.au/OC
Optimal Care Pathways	cancerpathways.org.au
Carer Gateway	carergateway.gov.au
Carers Australia	carersaustralia.com.au
Department of Health	health.gov.au
Department of Human Services	humanservices.gov.au
eviQ Cancer Treatments Online	eviq.org.au
Healthdirect Australia	healthdirect.gov.au
Look Good Feel Better	lgfb.org.au
<i>The Thing About Cancer</i> podcast	cancercouncil.com.au/podcasts

International

American Cancer Society	cancer.org
Macmillan Cancer Support (UK)	macmillan.org.uk
National Cancer Institute (US)	cancer.gov
Chemocare (US)	chemocare.com



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 depending on the situation. Being a carer can bring a sense of satisfaction, but it can also be challenging and stressful.

It is important to look after your own physical and emotional wellbeing. Give yourself some time out and share your concerns with somebody neutral such as a counsellor or your doctor, or try calling Cancer Council 13 11 20. There is a wide range of support available to help you with both the practical and emotional aspects of your caring role.

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 Associations – Carers Australia works with the Carers Associations in each state and territory to provide information and services to carers. Call 1800 242 636 or visit carersaustralia.com.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.



Question checklist

Asking your doctor questions will help you make an informed choice. You may want to include some of the questions below in your own list.

Treatment

- Why do I need chemotherapy?
- What are the advantages and disadvantages of chemotherapy for me?
- How successful is chemotherapy for the type of cancer I have?
- What is the goal of this chemotherapy?
- Are there any other treatments I can have instead?
- Is there any targeted therapy for the type of cancer I have?
- How much does treatment cost?
- What drugs will I be receiving? How will they be given?
- How often will I receive chemotherapy? How long will I have treatment?
- How will you decide the dosage?
- Are there clinical guidelines you are following?
- Where will I have chemotherapy? Can I have it close to where I live?
- How will we know if the treatment is working?

Side effects

- What are the risks and possible side effects of this treatment?
- Will chemotherapy affect my sex life and fertility?
- What can I do to help manage any side effects?
- Are there any complementary therapies that might help me?
- Who should I contact for information or if I have a problem during treatment? Who is my after-hours contact?

After treatment

- How often will I need check-ups after treatment?
- Am I at risk of developing late effects from chemotherapy? What might these be? What can I do to prevent this?



Glossary

adjuvant therapy

A treatment given with or shortly after the main treatment to enhance the main treatment's effectiveness.

advanced cancer

Cancer that has spread from its original site (primary cancer) to other parts of the body (secondary or metastatic cancer). It is unlikely to be cured.

alopecia

Hair loss.

anaemia

A low level of red blood cells.

antibody

A protein made by the blood in response to an invader (antigen) in the body. Antibodies are part of the body's immune system and help protect against viruses, bacteria and other foreign substances.

antiemetic

A drug that helps to control nausea and vomiting.

bone marrow

The soft, spongy material inside bones, which produces red blood cells, white blood cells and platelets.

cancer-related cognitive impairment

Thinking and memory problems that may be experienced after cancer treatment, including difficulty concentrating and focusing. Also called chemo brain or cancer fog.

cannula

A plastic tube inserted into a narrow opening (usually a vein) so that fluids can be introduced or removed.

cells

The basic building blocks of the body. A human is made of billions of cells that are adapted for different functions.

central line

A type of central venous access device used to give direct access to a vein in the chest or neck.

central venous access device (CVAD)

A type of thin plastic tube inserted into a vein. The CVAD gives access to a vein so fluid or chemotherapy can be given, and blood can be taken. Types of CVADs include central lines, Hickman lines, peripherally inserted central catheter (PICC) lines, and port-a-caths.

chemo brain

See cancer-related cognitive impairment.

chemoembolisation

See transarterial chemoembolisation (TACE).

chemoradiation

Treatment that combines chemotherapy with radiation therapy. Also called chemoradiotherapy.

chemotherapy

A cancer treatment that uses drugs to kill cancer cells or slow their growth. May be given alone or in combination with other treatments.

chemotherapy pump

A portable device that delivers a controlled amount of chemotherapy. It is usually attached to a central line. It allows a person to have chemotherapy at home.

cold cap

A cap that is connected to a cooling system and worn on the head during chemotherapy to help prevent hair loss.

complete response

The disappearance of all signs of cancer in response to treatment.

curative treatment

Treatment given with the aim of causing signs and symptoms of cancer to reduce or disappear.

cycle

Chemotherapy treatment session that is repeated on a regular schedule with periods of rest in between.

cytostatic

A substance (e.g. targeted therapy) that blocks the growth of cancer cells, but doesn't kill them.

cytotoxic

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

fatigue

Extreme feeling of tiredness and lack of energy. Often not eased by rest or sleep.

fertility

The ability to conceive a child.

first line chemotherapy

The first chemotherapy drug used to treat a person's cancer.

full blood count (FBC)

A test that measures the number, size and maturity of each type of cell in the blood. Sometimes called a complete blood count.

granulocyte-colony stimulating factor (G-CSF)

A protein that helps the bone marrow produce more neutrophils to reduce the risk of infection.

growth factor

A factor that stimulates the development and growth of cells.

haematologist

A doctor who specialises in studying and treating diseases of the blood, bone marrow and lymphatic system.

Hickman line

A type of central venous access device inserted into a vein in the chest.

hormone therapy

Treatment that blocks the body's natural hormones, which sometimes help certain cancers to grow. Also known as endocrine therapy.

immune system

A network of cells and organs that defends the body against attacks by foreign invaders, such as bacteria and viruses.

immunotherapy

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

intravenous (IV)

Inserted into a vein.

intravenous chemotherapy

Chemotherapy delivered into a vein through a drip or pump.

maintenance chemotherapy

Chemotherapy given for months or years as part of the treatment plan.

menopause

When a woman stops having periods (menstruating). This can happen naturally, from treatment, or because the ovaries have been removed.

metastasis (plural: metastases)

Cancer that has spread from a primary cancer to another part of the body. Also known as secondary cancer.

molecule

The smallest particle in a chemical element.

neoadjuvant therapy

A treatment given before another treatment to make that treatment more successful.

neutropenia

A low level of neutrophils. It can make you more prone to infections.

neutrophil

A type of white blood cell that defends the body against bacteria and yeast.

oncologist

A doctor who specialises in the study and treatment of cancer.

oral chemotherapy

Chemotherapy given by mouth as tablets or capsules.

palliative treatment

Medical treatment for people with advanced cancer to help them manage pain and other physical and emotional symptoms. Treatment may include chemotherapy, radiation therapy or other therapies.

peripherally inserted central catheter (PICC)

A type of central venous access device that is inserted into a vein in the arm.

peripheral neuropathy

Weakness, numbness, tingling or pain,

usually in the hands and feet, caused by damage to the nerves that are located away from the brain and spinal cord (peripheral nerves).

platelets

One of three types of cells found in the blood. Platelets help the blood to clot and stop bleeding. Also called thrombocytes.

port-a-cath (port)

A type of central venous access device. A thin tube put into a vein with an opening under the skin for delivering medicine.

radiation therapy

The use of targeted radiation to kill or damage cancer cells so they cannot grow, multiply or spread. The radiation is usually in the form of x-ray beams. Also called radiotherapy.

red blood cells

One of three types of cells found in the blood. They carry oxygen around the body. Also called erythrocytes.

remission

When the signs and symptoms of the cancer reduce or disappear.

second line chemotherapy

Chemotherapy that is given when first line chemotherapy doesn't work or the disease comes back.

side effect

Unintended effect of a drug or treatment.

steroid

A class of drugs used during cancer treatment to reduce inflammation; treat the cancer; relieve nausea, pain and

fatigue; and boost the appetite. Also called corticosteroids.

surgery

An operation by a surgeon to remove or repair a part of the body affected by cancer, create a stoma, or insert a prosthesis.

systemic treatment

Treatment that affects the whole body.

targeted therapy

Drug treatment attacks specific features known as molecular targets, to stop the cancer growing and spreading. Also called biological therapies or molecular targeted therapy.

thrombocytopenia

A low level of platelets. It can be a side effect of chemotherapy and makes you more prone to bleeding and bruising.

tissue

A collection of cells that make up an organ or structure in the body.

topical chemotherapy

Chemotherapy given as a lotion or cream applied to the skin.

transarterial chemoembolisation (TACE)

A treatment that injects chemotherapy directly into a tumour and blocks the tumour's blood supply.

treatment protocol

A detailed plan of a treatment. It outlines the drugs to be used, their dosage, the frequency, duration and side effects.

tumour

A new or abnormal growth of tissue on or in the body. A tumour may be benign (not cancer) or malignant (cancer).

white blood cells

One of three types of cells found in the blood. They help fight infection. Types of white blood cells include neutrophils, lymphocytes and monocytes. Also called leucocytes.

Can't find a word here?

For more cancer-related words, visit:

- cancercouncil.com.au/words
- cancervic.org.au/glossary
- cancersa.org.au/glossary

References

1. YY Lee et al., "Incidence and outcomes of pregnancy-associated cancer in Australia, 1994–2008: a population-based linkage study", *BJOG: An International Journal of Obstetrics and Gynaecology*, vol. 119, no. 13, 2012, pp. 1572–82.
2. FA Peccatori et al., "Cancer, pregnancy and fertility: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up", *Annals of Oncology*, vol. 24, suppl. 6, 2013, pp. vi160–70.



How you can help

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

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

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

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

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

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

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



Cancer Council

13 11 20

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

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

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

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

Cancer Council services and programs vary in each area.

13 11 20 is charged at a local call rate throughout Australia (except from mobiles).



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

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



Visit your local Cancer Council website

Cancer Council ACT
actcancer.org

Cancer Council NSW
cancercouncil.com.au

Cancer Council NT
nt.cancer.org.au

Cancer Council Queensland
cancerqld.org.au

Cancer Council SA
cancersa.org.au

Cancer Council Tasmania
cancertas.org.au

Cancer Council Victoria
cancervic.org.au

Cancer Council WA
cancerwa.asn.au

Cancer Council Australia
cancer.org.au

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