

# **Understanding Chemotherapy**

A guide for people with cancer, their families and friends

Treatment

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#### Understanding Chemotherapy

A guide for people with cancer, their families and friends

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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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#### 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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## Introduction

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 other questions to ask your treatment team.

This booklet does not need to be read from cover to cover – just read the parts that are useful to you. Some terms that may be unfamiliar are explained in the glossary. 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, as well as 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. Turn to the last page of this book for more details.

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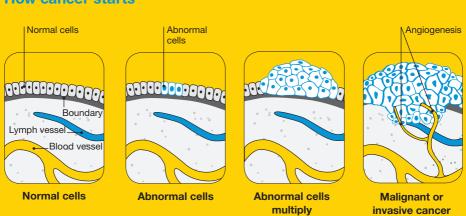


Cancer is a disease of the cells, which are the body's basic building blocks. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries. Normally, cells multiply and die in an orderly way.

Sometimes cells don't grow, divide and die in the usual way. This may cause blood or lymph fluid in the body to become abnormal, or form a lump called a tumour. A tumour can be benign or malignant.

**Benign tumour** – Cells are confined to one area and are not able to spread to other parts of the body. This is not cancer.

**Malignant tumour** – This is made up of cancerous cells, which have the ability to spread by travelling through the bloodstream or lymphatic system (lymph fluid).

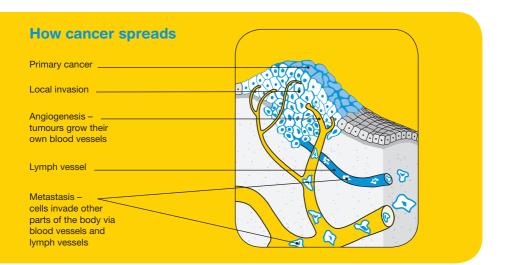


#### How cancer starts

The cancer that first develops in a tissue or organ is called the primary cancer. A malignant tumour is usually named after the organ or type of cell affected.

A malignant tumour that has not spread to other parts of the body is called localised cancer. A tumour may invade deeper into surrounding tissue and can grow its own blood vessels, a process known as angiogenesis.

If cancerous 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, breast cancer that has spread to the liver is called metastatic breast cancer, even though the person may be experiencing symptoms caused by problems in the liver.



# **Bow is cancer treated?**

Different treatments for cancer are used alone or in combination. Most cancers are treated with surgery, chemotherapy and/ or radiotherapy. Other treatments, such as hormone therapy and immunotherapy, can also be used for some types of cancer. Sometimes targeted therapy is used instead of or with chemotherapy. Cancer treatments can be given with a range of aims (see page 9).

Main types of cancer treatments		
Surgery	An operation to remove or repair a part of the body affected by cancer.	
Chemotherapy	The use of cytotoxic drugs (see page 8) to treat cancer by killing cancer cells or slowing their growth.	
Radiotherapy (radiation therapy)	The use of radiation, usually x-rays or gamma rays, to kill cancer cells or injure them so they cannot grow and multiply.	
Hormone therapy (endocrine therapy)	Treatment that blocks the body's natural hormones, which sometimes help cancer cells grow. It is used when the cancer is growing in response to hormones.	
Immunotherapy	The prevention or treatment of disease using substances that alter the immune system's response.	
Targeted therapy	Treatment that attacks specific particles (molecules) within cells that allow cancer to grow. Some immunotherapy and hormone therapy drugs are types of targeted therapy.	

#### Your treatments

The treatments you have depend on several factors, including:

- the type of cancer you have
- where it began
- whether it has spread to other parts of your body
- your general health
- your age
- what treatments are currently available
- your preferences.

Cancer Council has information about different cancer types and their treatments, as well as booklets about surgery and radiotherapy. Call Cancer Council 13 11 20 for free copies of these resources, or download them from your local Cancer Council website.

#### **Chemotherapy for children**

This booklet has been written primarily for adults having chemotherapy, although some of the information will also be relevant for children. Talk to your treatment team for specific information about chemotherapy for children. You might also want to get in touch with Camp Quality or CanTeen for age-appropriate resources and support:

- Camp Quality for children aged 0-13 who are living with cancer and their families, Call 1300 662 267 or visit campguality.org.au.
- CanTeen for young people aged 12-24 who have been affected by cancer. Call 1800 226 833 or visit canteen.org.au.



## **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 are obtained from natural sources such as plants, while others are completely created in a laboratory.

## Q: How does it work?

A: Most chemotherapy drugs enter the bloodstream and travel throughout the body to reach cancer cells in the organs and tissues. Sometimes chemotherapy is delivered directly at the tumour site rather than via the bloodstream (see page 22).

Chemotherapy drugs damage cells as they divide. This makes the drugs effective against cancer cells, which divide much more rapidly than most normal cells do. However, some normal cells – such as hair follicles, bloods cells, and cells inside the mouth or bowel – also divide rapidly. Side effects occur when chemotherapy damages these normal cells (see pages 33–53). Unlike cancer cells, normal cells can recover, so most side effects are temporary.

## Q: How is chemotherapy given?

A: Chemotherapy is most often given via a vein (intravenously). It is sometimes given in other ways, such as by mouth as tablets (orally), as a cream, or as injections into different parts of the body. For more information, see pages 18–23.

## Q: Why have chemotherapy?

A: Chemotherapy can be used for different reasons:

**To achieve remission or cure** – In many cases, the aim of chemotherapy is to cause the signs and symptoms of cancer to reduce or disappear (remission). The treatment may be called curative chemotherapy. It could be given either on its own or with other treatments, such as surgery and radiotherapy.

**To help other treatments** – Chemotherapy is sometimes given either before or after other treatments. Used before (neoadjuvant therapy), its purpose is to reduce the cancer so your main treatment is more effective. If chemotherapy is given after your main treatment (adjuvant therapy), its aim is to get rid of any remaining cancer cells.

**To control the cancer** – Even if chemotherapy cannot achieve remission (see above), it may be used to control the cancer's growth and stop it spreading for an extended period of time. This may be called palliative chemotherapy.

**To relieve symptoms** – By shrinking a tumour 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 be given for months or years after the initial chemotherapy has achieved remission of the cancer. This is called maintenance chemotherapy. It aims to prevent or delay the cancer returning.

## **Q: Does chemotherapy hurt?**

A: Having intravenous chemotherapy may feel like having your blood taken. If you have a temporary tube (cannula) in your hand or arm, only the initial injection may hurt. If you have a central venous access device, it should not be painful. See pages 20–21 for an explanation of these methods.

Some types of chemotherapy will cause side effects. However, there are ways to manage these (see pages 33–53). The drugs used for chemotherapy are constantly being improved to give you the best possible results and to reduce potential side effects.

## **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 21) or have oral chemotherapy can have their treatment at home. Some programs provide a visiting nurse to give chemotherapy in your home. Your treatment team will discuss which options are available to you.

## **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 sessions to try to destroy all the cancer cells, and these may be daily, weekly or monthly. Chemotherapy is commonly given in courses (cycles), with rest periods in between. This allows normal cells to recover and your body to regain its strength. If your body needs more time to recover, your next cycle may be delayed.

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

#### When to call your treatment team or 000

Chemotherapy can temporarily affect the white blood cells that usually fight infection, so even a minor infection can rapidly become serious. Let your GP or treating specialist know if you have symptoms that may indicate an infection (e.g. sore throat, night sweats, stinging on passing urine, easy bruising). Contact them urgently or call 000 if you have any of these symptoms:

- a temperature of 38°C or above
- persistent or severe nausea or vomiting
- redness or swelling around the site of the intravenous chemotherapy device or the previous injection
- shaking chills
- severe abdominal pain, constipation or diarrhoea
- unusual bleeding (e.g. nose bleeding for over 30 minutes)
- any serious unexpected side effects or sudden deterioration in health.

### 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.



#### Look after yourself

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



#### Sort out work

If you are working, talk to your employer about what 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.

#### 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.





#### **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.

#### Arrange transport

Plan how you will get to chemo sessions. If travelling by car, ask about parking. Since you won't know how you will feel, it is best to arrange a driver for at least your first session. You can call Cancer Council **13 11 20** to find out if there are transport to treatment services in your area.



#### 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. Consider asking one friend or family member to coordinate offers of help.



#### Pack a chemo bag

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

# $\frown$

Check other medicines Make sure your doctor 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.

#### **Discuss your concerns**

Keep a list of questions for your oncologist and add to it whenever a new question occurs to you. If you are feeling anxious about the diagnosis and treatment, try talking to a family member or friend, or to your GP or another member of your health care team.



## Prepare for side effects

Talk to your treatment team about the likely side effects of the chemotherapy drugs you are having. Ask whether you should take medicine to prevent nausea and vomiting. If you may lose your hair, think about whether you want to choose a wig, hats or scarves before treatment starts.

#### 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 health care team about your options before chemotherapy begins (see page 52).

Key questions 13

## **Q: How much does treatment cost?**

A: Chemotherapy drugs are expensive, but most people pay only a fraction of the cost as many drugs are heavily subsidised by the Pharmaceutical Benefits Scheme (PBS). However, there are some drugs that are not covered by the PBS.

Ask your specialist or treatment centre for a written quote that shows what you will have to pay. You will usually have to cover the cost of any medicines that you take at home to relieve the side effects of chemotherapy (such as anti-nausea medicine).

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 drugs. Check with your doctor and health fund before you start treatment.

# Q: Can I have chemotherapy during pregnancy?

A: Being diagnosed with cancer during pregnancy is rare. In Australia, about one in 2500 women is affected.<sup>1</sup>

It is possible for some pregnant women to have chemotherapy. 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. Sometimes chemotherapy or other treatment can be delayed until after the baby's birth. If you have chemotherapy during pregnancy, your doctor will probably advise you 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.

Researchers are currently doing long-term studies on women and children to explore this issue further. 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 children who were exposed to chemotherapy in the womb during the second and third trimesters show that chemotherapy did not affect their development.<sup>2</sup>

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. 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.

# 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. Check with your doctor how soon your treatment should start, and take as much time as you can before making a decision.

Understanding the disease, the available treatments and possible side effects can help you weigh up the pros and cons of different treatments and make a well-informed decision that's based on your personal values. You may also want to discuss the options with your doctor, friends and family.

You have the right to accept or refuse any treatment offered. Some people with more advanced cancer choose treatment even if it offers only a small benefit for a short period of time. Others want to make sure the benefits outweigh the side effects so that they have the best possible quality of life.

## **Talking with doctors**

When your doctor first tells you that you have cancer, you may not remember the details about what you are told. Taking notes or recording the discussion may help. Many people like to have a family member or friend go with them to take part in the discussion, take notes or simply listen.

If you are confused or want clarification, you can ask for further explanation – see page 60 for a list of suggested questions. If you have several questions, you may want to talk to a nurse or ask the office manager if it is possible to book a longer appointment.

## A second opinion

You may want to get a second opinion from another specialist to confirm or clarify your doctor's recommendations or reassure you that you have explored all of your options. Specialists are used to people doing this.

Your doctor 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 doctor who provided the second opinion.

## Taking part in 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.

It may be helpful to talk to your specialist or clinical trials nurse, or to get a second opinion. If you decide to take part, you can withdraw at any time. For more information, call Cancer Council 13 11 20 for a free copy of *Understanding Clinical Trials and Research*, or visit australiancancertrials.gov.au.



Most chemotherapy is given as a liquid drip into your vein (intravenously, see below), but it is sometimes given by mouth (orally) or in another way (see pages 22–23).

You may have one drug or a combination of drugs. Different drugs and combinations are effective for different cancer types.

The choice of chemotherapy drugs, the dosage and the treatment schedule will be recorded in a treatment plan. In deciding on which drugs and dosage to give you, your treating specialist will usually consult clinical guidelines for your cancer type. These guidelines are based on the available evidence and aim to ensure the best possible outcomes. You can ask your specialist which guidelines they are following.

Your specialist may need to tailor your treatment according to your individual situation. Tests throughout treatment will monitor your response, and your treatment plan may be adjusted based on those results.

## **Intravenous (IV) chemotherapy**

Chemotherapy is most commonly given intravenously through a narrow tube (see pages 20–21). Depending on the treatment, a single session could take from 20 minutes up to several hours and will usually be given during day visits to your hospital or treatment centre. Sometimes chemotherapy is given continuously over a few days via a portable pump or device that you are able to use at home. Before chemotherapy, you may be given medicine so you don't feel sick (anti-nausea or anti-emetic medicine). You may also be encouraged to drink several glasses of water during the session. This helps ensure that the chemotherapy drugs don't sit in the kidneys or bladder too long. It is also a good idea to be well hydrated in case you later experience vomiting as a side effect.

You will probably be seated in a comfortable, padded lounge chair in a room with other patients when you are having chemotherapy. You are usually able to walk around the ward during the treatment session – for example, if you need to go to the toilet.

The nurses will assess you before chemotherapy, and monitor you during and after the session. They will let you know when you are able to leave the hospital or treatment centre. They will also talk to you about managing any side effects and tell you about any medicine you need to take at home.

Many people feel well enough to travel to and from chemotherapy sessions by themselves. Even so, it is recommended that a relative or friend comes with you to your first appointment to support you and help you get home in case you feel unwell. It is safe for family and friends to stay with you during the treatment.

• My chemo infusions took about eight hours because I had two drugs and a saline solution in between. It was a long day, sitting in the chair having infusions. I was lucky my partner stayed with me each time.  $99 \ Cheryl$ 

#### **Intravenous devices**

To prepare you for IV chemotherapy, you will have a narrow tube inserted, usually in a vein in your arm. This may be a short-term or longer-lasting device. 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, single-use plastic tube that is temporarily inserted into a vein using a needle. When the needle is removed, the cannula remains in place in your arm or the back of your hand. The cannula may be 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 entire course of treatment, often for several weeks to months. Blood for testing can sometimes be taken through this tube. 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.

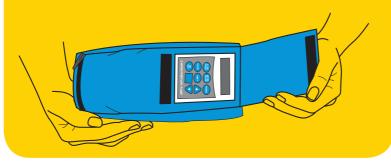
All tubes or lines need to be kept clean to prevent infection or blockage. If you have a CVAD, a nurse may visit you at home

to clean and dress your line, or this can be done at a hospital or treatment centre. Dressings usually happen weekly; how often the line needs rinsing with saline (flushing) depends on the device.

A CVAD doesn't cause pain or discomfort if it is properly placed and cared for, although you will be aware that it is there. Tell your doctor or nurse immediately if you have pain, discomfort, redness or swelling around the line. This could mean that you have an infection. In this case, you will be given medicine to help fight the infection and the device may need to be removed and replaced with a new one. If you do not experience any infections, the device will usually stay in place until after your last chemotherapy session.

#### **Portable pumps**

Some people are able to have chemotherapy at home using a portable pump. The pump is programmed to give the prescribed amount of chemotherapy over a specified period. The pump is usually attached to a central line and can be carried in a bag or belt holster. Your hospital or treatment centre will explain how to care for the pump.



## Other chemotherapy methods

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

**Oral chemotherapy** – Some people take chemotherapy tablets or capsules at home. Your doctor, nurse or pharmacist will tell you how and when to take them, how to handle the medicine safely, and what side effects might occur.

**Cream** – Some skin cancers are treated using a chemotherapy cream applied directly to the skin.

**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.

**Chemoembolisation** – Used for liver cancer or some types of cancer that have spread to the liver, chemoembolisation involves injecting chemotherapy directly into the blood vessels supplying a tumour. The chemotherapy is mixed with tiny spheres that block the vessels and stop the tumour getting nutrients and oxygen.

**Chemotherapy wafers** – Some people who have surgery for a brain tumour (craniotomy) will have small, soluble gel wafers of chemotherapy placed into the tumour site during the operation.

## **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 radiotherapy.

**High-dose chemotherapy** – This is a treatment given as part of a stem cell transplant for blood cancers, such as leukaemia or lymphoma. The high-dose chemotherapy kills off all the cancer cells before the new, healthy blood cells are transplanted. The transplant may occur a day or two or several days later.

**Chemoradiotherapy or chemoradiation** – Chemotherapy is given during the course of radiotherapy for some cancers, such as bowel cancer. It aims to make the radiotherapy more effective.

#### **Smoking and chemotherapy**

If you smoke, it's best to try to quit, especially while you are having chemotherapy. It can seem like a tough time to stop smoking, but research shows that people who have never smoked or ex-smokers have a better survival rate from cancer than smokers. Smoking during chemotherapy may reduce the effectiveness of the treatment. For advice, talk to your doctor, call **13 QUIT (13 7848)** or visit **quitnow.gov.au**.

## Waiting for chemotherapy

When you have chemotherapy, you may spend a lot of time waiting, usually in the hospital or treatment centre: 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 you might want to bring your own water bottle and snacks in case of long delays.

To pass the time, you may want to do the following:

- read a book or magazine, or listen to music
- 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 find support from others who are receiving chemotherapy at the same time as them.

● I became good friends with another 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*  Tell your doctor if you plan to take over-the-counter medicines, home remedies or complementary therapies, such as herbal or nutritional supplements, before or after your chemotherapy treatment. These may make side effects worse or affect how well the chemotherapy works in your body.

## **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 types 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 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 while at home. Safety precautions can vary depending on the drugs you receive, so ask your treatment team about your individual situation.



down to use the toilet. Put the lid down before flushing to avoid splashing. Vomit into a plastic bowl or bucket (or a

For a week after a treatment session, sit

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

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.



During the week after a treatment session, wear disposable waterproof gloves when handling clothing or bed sheets soiled with vomit or other body fluids, such as urine or faeces. Seal the gloves in a plastic bag and discard after use. Wash items soiled with body fluids in a separate load in a washing machine on the longest cycle (hot or cold water can be used). Line dry the items.

Use a condom or a female condom if having any type of sex within 7 days of a chemotherapy session. Your doctor or nurse can give you more detail about when you need to use protection.

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

Don't crush, chew or cut chemotherapy tablets. If you can't swallow a tablet whole, talk to your treatment team or pharmacist.

Store all chemotherapy tablets, capsules or injections as directed by your doctor 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.













Many people are given steroid medicine with their chemotherapy treatment, most often in a low dose to help ease or prevent nausea. Steroids are sometimes also used to manage allergic reactions, to make chemotherapy more effective, or to directly treat the cancer.

## **Targeted therapy**

Targeted therapy may be used instead of or together with chemotherapy. This treatment uses drugs that work in a different way to chemotherapy drugs. While chemotherapy affects all rapidly dividing cells and works by killing cancerous cells (cytotoxic), targeted therapy targets specific molecules within cells and often works by blocking cell growth (cytostatic).

Although targeted therapy minimises harm to healthy cells, it can still have side effects (see below). Not all cancers respond to targeted therapy, and the drugs are sometimes hard to access because they are expensive, not yet developed for all types of cancer, and sometimes available only in clinical trials (see page 17).

Cancer cells often become resistant to targeted therapy drugs. If this happens, your doctor will change your treatment and may suggest trying chemotherapy or another type of targeted therapy.

#### Side effects of targeted therapy

Side effects vary depending on the targeted therapy used, but may include fevers, allergic reactions, rashes, diarrhoea, blood-clotting problems, and blood pressure changes. Particular drugs can affect the way your heart or liver works. Some side effects that are of little concern after standard chemotherapy can be very serious if they occur with a targeted therapy – your doctor will explain what to watch out for, and will monitor you throughout the treatment.

#### Types of targeted therapy

There are currently two main types of targeted therapy: monoclonal antibodies and small molecule inhibitors.

#### **Monoclonal antibodies**

- act like the natural antibodies that our bodies produce to fight infection and disease but are made in a laboratory (synthetic)
- lock onto a protein on the surface of certain cells and interfere with the growth or survival of cancer cells in some way, e.g. may deliver a toxic drug to cancer cells, interrupt the growth and spread of cancer cells, or prompt cells of the immune system to attack cancer cells
- given intravenously or as an injection under the skin (subcutaneous injection)
- drug names end in '-mab' (for monoclonal antibody),
   e.g. bevacizumab, rituximab

#### **Small molecule inhibitors**

- can get inside cancer cells and block certain proteins and enzymes that tell the cancer cells to grow
- include tyrosine kinase inhibitors (TKIs) – these block the function of a group of enzymes called tyrosine kinases, which tell cancer cells to grow, multiply and spread
- given as tablets or capsules to be taken by mouth, usually on a daily basis over months or years
- drug names end in '-ib' (for inhibitor), e.g. imatinib, sorafenib

## 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 will use 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, 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 may continue for a period of time. Once your chemotherapy treatment has finished, your treatment team will monitor you for several months or years. This is because cancer can sometimes come back in the same place or grow in another part of the body.

## Which health professionals will I see?

You will be cared for by a range of health professionals during chemotherapy. This is called a multidisciplinary team (MDT) and it may include some or all of the professionals listed opposite. Note that only some patients see a cancer care coordinator.

It is important to maintain or develop a relationship with a regular general practitioner (GP), as they will be involved in your ongoing care, particularly once the cancer treatment finishes.

Health professional	Role
GP	refers you to specialists and provides ongoing care during and after your treatment
medical oncologist* or haematologist*	prescribes and coordinates the course of chemotherapy
radiation oncologist*	prescribes and coordinates radiotherapy (which is sometimes given with chemotherapy)
cancer care coordinator or clinical nurse consultant (CNC)	coordinates your care, liaises with other members of the MDT, and supports you and your family throughout treatment
nurses	administer drugs, including chemotherapy, and provide care, information and support throughout your treatment
nurse practitioner	nurse who has had additional training and may be able to prescribe some medicines and refer you to other health professionals
palliative care specialist* and palliative care nurses	work closely with the GP and oncologist or haematologist to help control symptoms and maintain quality of life
pharmacist	dispenses medicines and gives advice about dosage and side effects
dietitian	recommends an eating plan to follow while you are in treatment and recovery
occupational therapist, physiotherapist	assist with physical and practical problems
social worker	links you to support services and helps with emotional, physical or practical issues
psychologist, counsellor	provide emotional support and help manage anxiety and depression

\* Specialist doctor



#### **Key points**

- Chemotherapy is most commonly given via a tube into a vein (intravenously).
- You may have one drug or a combination of drugs depending on the cancer type.
- Usually people will have intravenous chemotherapy as an outpatient at a hospital or treatment centre, but sometimes they can have it at home using a portable pump.
- 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, chemoembolisation for liver cancer, or wafers for brain cancer.
- 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 to make sure your family members don't come into contact with your body fluids, such as urine or vomit, as the drugs may be passed into them. You should also handle chemotherapy drugs with care.
- Targeted therapy may be used instead of or with chemotherapy. The drugs target specific molecules within cancer cells.
- You will see a range of health professionals when you have chemotherapy. As well as your GP, these will include a medical oncologist or haematologist, nurses and other health professionals.

# Managing side effects

While chemotherapy can kill cancer cells, it can also affect normal cells that grow or divide rapidly, such as the new blood cells in the bone marrow and the cells in the mouth, stomach, skin, hair and reproductive organs. When the normal cells are damaged, this causes side effects.

Whether or not you have side effects, and how severe they are, depends on the type and dose of drugs you are given and how you react individually from one treatment cycle to the next. Most side effects are temporary and can be managed. They tend to gradually disappear once treatment stops and the normal healthy cells recover.

#### Why chemotherapy affects the blood

Chemotherapy can affect the production of blood cells. The three main types of blood cells have specific functions:

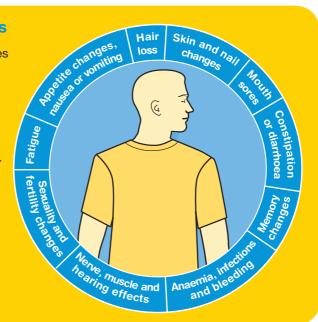
- red blood cells carry oxygen around the body
- white blood cells fight infection
- platelets help blood to clot and prevent bruising.

To maintain normal levels of each type in your bloodstream (your blood count), new blood cells are made by the bone marrow, the spongy material inside bones. Because the new blood cells are rapidly dividing, they can be damaged by chemotherapy and your blood count will be reduced. This may cause anaemia, infections or bleeding problems (see pages 46–48).

You will have blood tests to check that your blood count has returned to normal before your next chemo session.

#### **Common issues**

This chapter discusses the most common side effects people experience from chemotherapy and offers suggestions to help manage them.



#### **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, what medicine to take to help prevent or manage them, and who to contact after hours.

If the side effects change your appearance and self-esteem, consider attending the free Look Good Feel Better program. For more details and to book, call 1800 650 960 or visit lgfb.org.au.

## **Chemotherapy diary**

It can be useful to record information about 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 reduce them. Some people use a notebook or a diary, while others prefer to use technology such as 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 they may adjust your treatment, if appropriate.

## **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 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.

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 worsen side effects. Complementary therapies are different to alternative therapies, which are used instead of conventional medical treatments. Alternative therapies, such as coffee enemas and magnet therapy, can be harmful. For more information, call 13 11 20 and ask for a free copy of the *Understanding Complementary Therapies* booklet, or download a digital version from your local Cancer Council website.

# Feeling tired and lacking energy

Feeling tired and lacking energy (fatigue) is the most common and often the most debilitating 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.

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### Tips for managing fatigue

- Work out your priorities, so you save your energy for the most important things.
- Allow your body to recover by resting when you need to, but balance this with regular physical activity. Exercise can reduce treatment-related fatigue and can also help with other common side effects, such as nausea and loss of appetite.
- Aim to fit in some light exercise, such as walking, on most days and/or keep up with your normal exercise routine. Talk to your health care team about suitable activities for you. You can also call Cancer Council
   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.

- Let people help you. Family, friends and neighbours often want to assist but may feel unsure about what to do. They could ease your load by helping 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.
- Plan activities for the time of day when you tend to feel most energetic.

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 55). If you think you may be depressed, it's important to talk to your health care team as there are treatment options available.

- Try to eat a well-balanced diet with plenty of fruits and vegetables.
- Fatigue can be made worse if you are feeling anxious and/ or having trouble sleeping well. Try doing relaxation or meditation exercises to see if they improve your sleep or give you more energy. Call
   13 11 20 and check whether your local Cancer Council can provide CDs or other resources that may help.
- Consider whether you would like to try acupuncture, which some studies suggest may help reduce physical tiredness after chemotherapy.

- Chemotherapy sometimes causes a poor appetite, nausea and/or vomiting, all of which can leave you feeling exhausted. See the next two pages for tips.
- Check with your doctor whether your fatigue is related to low levels of red blood cells (anaemia). Anaemia can be treated (see page 46).
- 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 work, 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, and the drugs may 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.



## Tips for coping with nausea and changed appetite

- If you are nauseous or have vomited a lot, try to 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.
- Eat a light meal before your treatment (e.g. soup with dry biscuits or toast), and drink as much fluid as possible.

- Sip fluids throughout the day, rather than trying to drink a lot at once. Sucking on ice cubes, iceblocks or jellies can also increase your fluid intake.
- 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 a slice of toast rather than skipping food.
- Breathe deeply and gently through your mouth if you feel like you're going to vomit.

Often the best way to manage nausea is to stop it before it starts. Anti-nausea (anti-emetic) medicine helps most people, but finding the right one can take time. If you still have nausea or vomiting after using the prescribed medicine, let your nurse or doctor know so that another medicine can be tried.

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 best not to be left alone if you are vomiting a lot, as the confusion may make it difficult to realise you have become seriously dehydrated.

- Eat what you feel like, when you feel like it. Have frequent snacks instead of large meals.
- Avoid strong odours and cooking smells. Prepare meals ahead and freeze them for days you don't feel like cooking.
- Eat and drink slowly. Chew your food well to make it easier to digest.
- Consider trying acupuncture, which research shows can reduce chemotherapy-related nausea and vomiting.

- 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.
- Speak to the hospital dietitian for advice about eating.
- Call Cancer Council **13 11 20** for copies of the *Nutrition and Cancer* booklet and the *Understanding Taste and Smell Changes* fact sheet, or find digital versions on your local Cancer Council website.

# **Hair loss**

Many people having chemotherapy worry about hair loss. Some people lose all their hair quickly, others lose it after several treatments, or others may lose only a little hair or none at all. Ask your doctor if hair loss is a possibility and how you can prepare.

When hair loss does occur, it usually starts 2–3 weeks after the first treatment and grows back when chemotherapy is completed. 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.



## 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 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. You could also consider shaving your head. 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, or to collect hair.
- Use a cotton, polyester or satin pillowcase, as nylon can irritate your scalp. If you prefer to leave your head bare, protect it against sunburn and the cold.

Although losing head hair is most common, you may also lose hair from your eyebrows, eyelashes, arms, legs, chest and pubic region.

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 normal condition.

Many people find losing their hair difficult. You may see your hair as part of your overall image and its loss can make you feel sad or vulnerable. Talking to your treatment team may help.

- 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 vegetablebased, 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.

- Consider choosing a wig before chemotherapy starts.
   Call Cancer Council 13 11 20 for assistance in finding a wig library or shop.
- Consider booking in for a Look Good Feel Better workshop, where you can try on wigs and hair coverings and learn new make-up techniques. Visit Igfb.org.au or call 1800 650 960.
- Read Cancer Council's Hair Loss fact sheet.

# Skin and nail changes

Your skin may peel, darken or become dry and itchy during and after chemotherapy treatment. It is also likely to be more sensitive to the sun.

Some people find their nails also change and become brittle and dry, develop ridges, or have white lines across them.

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## 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.
- 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, especially between 10am and 3pm. 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, tell your doctor or nurse immediately.
- Avoid chlorinated swimming pools as the water can make skin changes worse.

# **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 radiotherapy to the head, neck or chest, or if you have dental or gum problems. If you notice any change in your mouth or throat, such as sores, ulcers or thickened saliva, or if you find it difficult to swallow, contact your doctor.

### **Tips for mouth care**

- Discuss any dental problems with your doctor before seeing the dentist. If you need any dental work, tell your dentist you are having chemotherapy.
- Use a soft toothbrush to clean your teeth twice a day.
- Try a homemade mouthwash (1 tsp bicarbonate of soda or salt in a glass of warm water) four times a day. Avoid mouthwashes with 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 and mouth with plain yoghurt.
- Blend foods to make them easier to eat. Try smoothies with 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.

# **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
• Eat more high-fibre foods,	<ul> <li>Choose bla</li></ul>
such as wholegrain bread	as clear bro
and pasta, bran, fruits and	Avoid spicy
vegetables, nuts and legumes	products, fa
(e.g. baked beans or lentils).	foods, rich
• Drink plenty of fluids, both	fruits or veg
warm and cold, to help loosen	skins or see
the bowels. Prune, apple or	• Limit alcoho
pear juice can work well.	drinks, stror
<ul> <li>Do some light exercise,</li></ul>	and dairy p
such as walking.	stimulate th
<ul> <li>Don't use enemas or</li></ul>	<ul> <li>Drink water</li></ul>
suppositories. They are not	fluids lost the flui
recommended for people having chemotherapy.	Talk to your about using
• Let your treatment team know	medicines f

 Let your treatment team know if you have constipation for more than a couple of days. They will be able to help.

- 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 pharmacist about using over-the-counter medicines for diarrhoea.
- If diarrhoea is severe, it can cause dehydration and you may need to go to hospital.

# Memory and concentration changes

Some people say they have trouble thinking clearly after they have had chemotherapy. This is called cognitive impairment or, sometimes, 'chemo brain'. You may find that it takes you more time to process information, or you may experience short-term memory loss or have trouble concentrating for long periods. This side effect may last for a short time or for years.

There is some evidence that self-help techniques such as exercise, relaxation, and memory games can help. Tell your doctor if this issue is affecting your day-to-day life.

## 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.
- Plan to do things that require focus when you are fresher, such as in the morning. At other times, choose activities that need less concentration, e.g. read magazines instead of complex novels.

- Get plenty of sleep. Deep sleep is important for memory and concentration.
- Do light exercise each day. This may help you to clear your mind and sleep better.
- Learn something new, e.g. take up a new hobby or do crosswords or puzzles.
- Talk to your partner, family or friends about how you're feeling. This can help prevent misunderstandings and frustration.

# Anaemia

A low red blood cell count is called anaemia. This can make you feel tired, lethargic, dizzy or breathless. The tips for coping with fatigue on pages 36–37 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. If the levels 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 prone to infections and less able to fight any infections that do occur. Your doctor may recommend antibiotics as a precaution against infection.

The white blood cells known as neutrophils protect you against infection by destroying harmful bacteria and yeast that enter the body. A low level of neutrophils (neutropenia) is a common side effect of chemotherapy. If you have neutropenia, you may be given an injection of granulocyte-colony stimulating factor (G-CSF) after chemotherapy. 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 rapidly become serious. See page 11 for when you need to contact your doctor urgently.

## Tips for managing low immunity and infections

- Check your temperature every day and seek urgent medical attention if it rises to 38°C or above.
- See your doctor if you are unwell, even if you just have a cold.
- Wash hands well with soap and water before handling food and after using the toilet.
- Try to eat freshly cooked or freshly prepared foods. Avoid pre-made sandwiches, salads and takeaway; soft cheeses; raw or rare fish, meat or eggs; unpasteurised dairy foods; and soft-serve ice-creams.
- Use separate chopping boards and utensils for raw and cooked foods, and clean well with hot, soapy water.
- Wash fruits and vegetables well, or peel where possible.
- Store raw and cooked foods separately. Put leftover food in airtight containers in the fridge as soon as possible.

- Cook food thoroughly to reduce the risk of bacteria developing.
- Don't eat food or drinks past their use-by or best before dates.
- Stay away from people who are unwell, especially if they have the flu, conjunctivitis, measles, mumps, a cold sore or chickenpox. If a member of your household is unwell, try to avoid close contact until they have recovered.
- Try to avoid crowded places such as public transport during rush hour, shopping centres or public pools to reduce the risk of picking up an infection.
- Check with your doctor about having the flu vaccine if you are having chemotherapy during winter.
- Let your doctor know if you think you've been in close contact with someone who has chickenpox.

# **Bleeding problems**

Platelets are the blood cells that help the blood to clot, and 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 to go to hospital for a 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.

## 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 soft toothbrush to avoid irritating your gums.
- Avoid cuts and scrapes on your feet by wearing comfortable, well-fitting shoes indoors and outside.
- Take care when blowing your nose.
- If you bleed, apply pressure for about 10 minutes and bandage as needed.
- If you have problems with bleeding, talk to your doctor.

# Nerve and muscle effects

Some drugs can cause tingling ('pins and needles'), pain or loss of sensation in your fingers and/or toes, and muscle weakness in your legs. This is called peripheral neuropathy. If you experience these side effects, tell your doctor or nurse before your next treatment. Your treatment may need to be changed or the problem carefully monitored.

For many people, peripheral neuropathy is a short-term issue, but for others, it can last a long time or even be permanent. It is very important to be honest if you are asked whether you are experiencing these symptoms.

## Tips for managing peripheral neuropathy

- Take care when moving around – you may be more prone to trip and fall if your feet are numb or your legs are weak.
- Keep your hands and feet warm to help the blood circulate. Gloves and warm socks can help when it's cold.
- Soak your hands and feet in warm water to relieve symptoms.
- Make sure your shoes fit properly – tight shoes can

make the tingling worse, while loose shoes may make you stumble.

- 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. bed posts to raise the sheets off your feet.
- If your symptoms are severe, talk to your doctor about medicines that may offer relief.

# **Change in hearing**

Some chemotherapy drugs can affect your hearing. Your doctor may recommend that you have a hearing test before you start treatment. 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 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**

Many people have a range of worries that cause them 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, or there may be a physical reason for not being able or ready to have sex. For example, vaginal dryness or erection difficulties are common issues after treatment. Changes in appearance can also affect feelings of self-esteem and, in turn, sexuality.

For more information, call Cancer Council **13 11 20** and ask about free resources on sexuality and intimacy, or download them from your local Cancer Council website.

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 safety precautions described 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.

## Contraception

Although chemotherapy often reduces fertility, it is important to realise that it may not rule 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, so women should not become pregnant during the course of chemotherapy, and men should not father a child. Should you or your partner become pregnant, talk to your treating 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 condoms or female condoms, which provide protection against any chemotherapy drugs that may be excreted in their body fluids. Young women may be prescribed the contraceptive pill – as well as preventing pregnancy, the pill may help protect the ovaries from the effects of chemotherapy.

## **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.

For more information, call Cancer Council 13 11 20 and ask for a free copy of the *Fertility and Cancer* booklet, or download it from your local Cancer Council website.

### Effects on women

- For some women, periods become irregular during chemotherapy but return to normal after treatment.
   For others, 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.

#### Effects 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 get and keep an erection may also be affected, but this is usually temporary. If the problem is ongoing, talk to your doctor.

## **Key points**

- Many people experience side effects from chemotherapy.
   Side effects are caused when the chemotherapy damages rapidly dividing healthy cells.
- 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.
- It may be helpful to record your symptoms, when they occurred and what you did to relieve them, possibly in a chemotherapy diary. Show your notes to your doctor or nurse.
- Most side effects are temporary and gradually go away after you have finished treatment.
- Common side effects include feeling tired, loss of appetite,

nausea, hair loss, mouth sores, skin problems and bowel issues.

- You may have a reduced ability to concentrate or remember 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.
- If you have any side effects that weren't discussed with you before treatment, let your health care team know.



After chemotherapy has finished, your treatment team will give you general information about your recovery. They will recommend ways to manage side effects and who to call if you have any questions or concerns.

# **Follow-up appointments**

You will have regular check-ups with your treating specialist. These will become less frequent over time. During these appointments, you will usually have a physical examination and you may have blood tests, x-rays or scans to confirm that the cancer hasn't come back or spread. You will 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. Let your doctor know immediately if you experience any health problems between follow-up 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.

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

# **Coping with your emotions**

For most people, the cancer experience doesn't end on the last day of treatment. Life after cancer 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', but they don't want life to return to how it was before cancer. Take some time to adjust to the physical and emotional changes, and re-establish a new daily routine at your own pace.

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.

## **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 after cancer treatment.

Talk to your GP, as counselling or medication – even for a short time – may help. Some people are able to get a Medicare rebate for sessions with a psychologist. Ask your doctor if you are eligible. Your local Cancer Council may also run a counselling program.

The organisation beyondblue has information about coping with depression and anxiety. Go to **beyondblue.org.au** or call **1300 22 4636** to order a fact sheet.

# Cancer Council services

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

**Cancer Council 13 11 20** – This is many people's first point of contact if they have a cancer-related question. Trained professionals will answer any questions you have about your situation. For more information, see the inside back cover.

**Practical help** – Your local Cancer Council can help you access services or offer advice to manage the practical impact of a cancer diagnosis. This may include access to transport and accommodation or legal and financial support. Call 13 11 20 to find out what is available in your state or territory.

**Support services** – You might find it helpful to share your experiences with other people affected by cancer. For some people, this means joining a support group. Others prefer to talk to a trained volunteer who has had a similar cancer experience.

Cancer Council can link you with others by phone, in person or online at cancerconnections.com.au. Call us to find out what services are available in your area.

**Life after cancer** – It's natural to feel a bit lost after finishing treatment. You might notice every ache or pain and worry that the cancer is coming back.

Cancer Council can provide support and information to people adjusting to life after cancer – call 13 11 20 for details.

**Printed, online and audiovisual resources** – In addition to this resource, Cancer Council produces a wide variety of free information about cancer-related topics, including easy-to-read booklets and fact sheets on more than 20 types of cancer, treatment, emotional issues and recovery.

Cancer Council publications are developed in consultation with health professionals and consumers. Content is reviewed regularly, according to best practice guidelines for health information.

## **Related publications\***

You might also find the following free Cancer Council publications and audiovisual resources useful:

- Emotions and Cancer
- Nutrition and Cancer
- Exercise for People Living with Cancer
- Talking to Kids About Cancer
- Understanding Clinical Trials and Research
- Complementary Therapies
- Relaxation and meditation
   CDs

- Cancer, Work & You
- Overcoming Cancer Pain
- Caring for Someone
   with Cancer
- Sexuality, Intimacy and Cancer
- Living Well After Cancer
- Living with Advanced
   Cancer
- Understanding Palliative
   Care

Call **13 11 20** for copies, or download them from your local Cancer Council website.

\* May not be available in all states and territories.

# Caring for someone with cancer

You may be reading this booklet because you are caring for someone with cancer. Being a carer can be stressful and cause you much anxiety. Try to look after yourself – give yourself some time out and share your worries and concerns with somebody neutral, such as a counsellor or your doctor.

Many cancer support groups and cancer education programs are open to carers, as well as people with cancer. Support groups and programs can offer valuable opportunities to share experiences and ways of coping.

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

There are also many groups and organisations that can provide you with information and support, such as Carers Australia, the national body representing carers in Australia. Carers Australia works with the Carers Associations in each of the states and territories. Phone 1800 242 636 or visit carersaustralia.com.au for more information and resources.

You can call Cancer Council 13 11 20 to find out more about carers' services and support groups and to get a copy of the *Caring for Someone with Cancer* booklet.



The internet has many useful resources, although not all websites are reliable. The websites listed below are good sources of support and information.

## **Australian**

cancer.org.au
canceraustralia.gov.au
.cancerconnections.com.au
carergateway.gov.au
carersaustralia.com.au
health.gov.au
humanservices.gov.au
healthdirect.gov.au
lgfb.org.au

## International

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

# Question checklist

You may find this checklist helpful when thinking about the questions you want to ask your doctor about your disease and treatment. If your doctor gives you answers that you don't understand, ask for clarification.

- 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?
- Which clinical guidelines are you following?
- Where will I have chemotherapy? Can I have it close to where I live?
- What are the possible side effects of this treatment and what can I do to control them?
- Are there any complementary therapies that may help?
- How will I know if the treatment is working?
- Will chemotherapy affect my sex life and fertility?
- After treatment has finished, will I need check-ups?
- Who should I contact for information or if I have a problem during treatment? Who is my after-hours contact?



#### adjuvant therapy

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

#### 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.

#### biological therapy

A medicine made from purified versions of chemicals that are naturally made in the body. Types of biological therapy include monoclonal antibodies and immunotherapy drugs. Also called biotherapy.

#### bone marrow

The soft, spongy material inside bones. Bone marrow contains stem cells that produce red blood cells, white blood cells and platelets.

#### 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 blood 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.

#### chemotherapy

The use of cytotoxic drugs to treat cancer by killing cancer cells or slowing their growth. May be given alone or with other treatments.

#### chemotherapy pump

A portable device, usually attached to a central line. It allows a person to have chemotherapy at home.

#### cycle

The time between one chemotherapy treatment session and the next.

A substance (e.g. targeted therapy) that blocks the growth of cancer cells. cytotoxic

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

#### fertility

The ability to conceive a child.

# granulocyte-colony stimulating factor (G-CSF)

A protein that helps the bone marrow produce more neutrophils, the white blood cells that defend the body against bacteria and yeast.

#### **Hickman line**

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

#### hormone therapy/treatment

A treatment that blocks the body's natural hormones. It is used when the cancer is growing in response to hormones. Also known as endocrine therapy.

#### immunotherapy

The prevention or treatment of disease using substances that alter the immune system's response. May also be called biological therapy.

#### infusion

A slow injection of a substance into a vein or other tissue.

intravenous (IV) Inserted into a vein.

#### menopause

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

#### molecule

A very small particle in a chemical element.

#### monoclonal antibodies

A group of targeted therapy drugs that lock onto a specific protein on the surface of cancer cells and interfere with the cells' growth or survival.

#### neoadjuvant therapy

A treatment given before the main treatment to try to make the main treatment more successful.

#### neutropenia

A low level of neutrophils. It can be a side effect of chemotherapy and makes you more prone to infections. **neutrophils** 

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.

#### palliative treatment

Medical treatment for people with advanced cancer to help manage pain and other symptoms. Treatment may include chemotherapy, radiotherapy or other therapies. It is an important part of palliative care.

# 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). This damage can be a side effect of chemotherapy.

#### platelets

Cells found in the blood that 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.

#### radiotherapy

The use of radiation to kill cancer cells or injure them so they cannot grow and multiply. Also called radiation therapy. red blood cells

Cells found in the blood that carry oxygen around the body. Also called erythrocytes.

#### remission

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

#### side effect

Unintended effect of a drug or treatment.

#### small molecule inhibitors

A group of targeted therapy drugs that can get inside cancer cells and block proteins that tell the cells to grow.

#### steroid

A class of drugs mostly used for inflammation, but also used to treat myeloma. Also called corticosteroids.

#### targeted therapy

Treatment that attacks specific particles (molecules) within cells that allow cancer to grow and spread. The two main types of targeted therapy at present are monoclonal antibodies and small molecule inhibitors.

#### 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 a part of the body.

#### tumour

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

#### tyrosine kinase inhibitor (TKI)

A small molecule inhibitor that blocks enzymes involved with cell growth. A targeted therapy.

#### white blood cells

Cells found in the blood that 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, 2012, pp. 1572–82.
- 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, 2014, 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 Pink Ribbon Day, 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, contact us through the National Relay Service. www.relayservice.gov.au



For information and support on cancer-related issues, call Cancer Council **13 11 20**. This is a confidential service.

## 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.