

Coping with Chemotherapy

For people with cancer,
their family and friends



Coping with chemotherapy

Cancer Council Victoria 2010. Coping with chemotherapy: for people with cancer, their family and friends. Melbourne. Cancer Council Victoria.

First published June 1995

This edition April 2010

This booklet is available online – visit www.cancervic.org.au

Interpreting service: Deaf or hearing or speech impaired

If you use text-based communication, call the Cancer Council Helpline (13 11 20) through the National Relay Service (NRS) 13 3677. If you can hear and still use your voice, but have a speech impairment, call the Cancer Council Helpline through NRS 1300 555 727.

Acknowledgments

The Cancer Council thanks everyone who contributed to the development and revisions of this booklet.

Generous Victorians who fundraise to fight cancer make many Cancer Council services, including the publication of this booklet, possible. For information on how you can help, visit www.cancervic.org.au or call 1300 65 65 85.

Introduction

This booklet has been prepared to help you understand more about chemotherapy, one of the main treatments for cancer.

Understanding chemotherapy may help you cope better and help you decide about treatment.

People react in different ways to chemotherapy. You may have only mild side effects, or it may cause you some difficulty. There are things you can do to prevent or reduce side effects.

We cannot tell you which is the best treatment for you. You need to discuss this with your doctors. However, we hope this booklet will answer some of your questions and help you think about the questions you want to ask your doctors.

You may like to pass this booklet on to your family and friends.

This booklet does not need to be read from cover to cover but can be read in sections according to your needs or interest. The words in **bold** are explained in the glossary at the back of this booklet.

*** Are you reading this for someone who does not understand English? Tell them about the Multilingual Cancer Information Line. See the inside back cover for details.**

Contents

What is cancer?	...4
How cancer is treated	...6
Chemotherapy and why it is used	...7
Doctors and other health professionals you may see	8
How is chemotherapy given?	9
How does chemotherapy work?	11
Does having chemotherapy hurt?	11
Chemotherapy can be time-consuming	12
How will I know if the treatment has worked?	12
Side effects of chemotherapy	...14
Fatigue	15
Nausea and vomiting	16
Bowel problems	17
Mouth problems	18
Hair loss and scalp problems	19
Cognitive problems ('chemo brain')	20
Effects on the blood	21
Muscle and nerve effects	23
Fertility	23
Special issues	...24
Contraception	24
Protecting others from chemotherapy	24
Diet	25

Fluids	25
Alcohol	26
Skin care	26
Taking part in a clinical trial	26
Complementary and alternative medicines	27

Seeking support ...29

Follow-up care	29
Practical and financial help	30
Wigs	30
Exercise	31
Relaxing	31
Sexuality and cancer	31
Cancer Council Helpline	32
Multilingual Cancer Information Line	32
Talk to someone who has been there	33
Living with Cancer Education Program	34

Caring for someone with cancer ...35

Your personal chemotherapy record ...37

Current Medication Record	38
Weekly Chemotherapy Journal	39
Test Results	40
Contacts	41
Appointments	42

Glossary: what does that word mean? ...43

Index ...47

What is cancer?

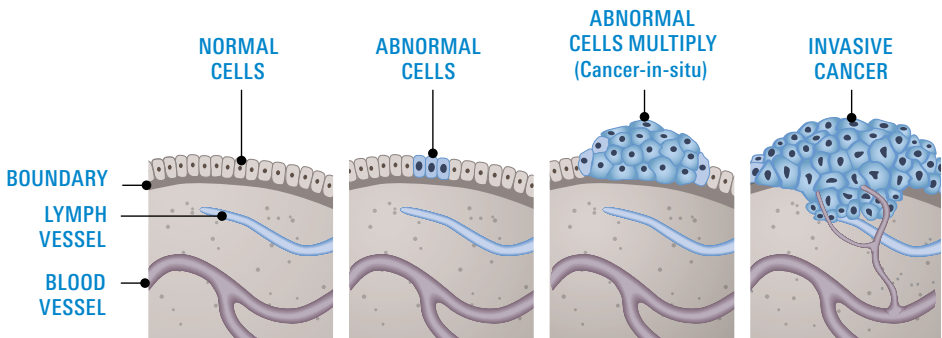
Cancer is a disease of the body's cells. Our bodies are always making new cells: so we can grow, to replace worn-out cells, or to heal damaged cells after an injury. This process is controlled by certain **genes**. All cancers are caused by changes to these genes. Changes usually happen during our lifetime, although a small number of people inherit such a change from a parent.

Normally, cells grow and multiply in an orderly way. However, changed genes can cause them to behave abnormally. They may grow into a lump. These lumps can be **benign** (not cancerous) or **malignant** (cancerous).

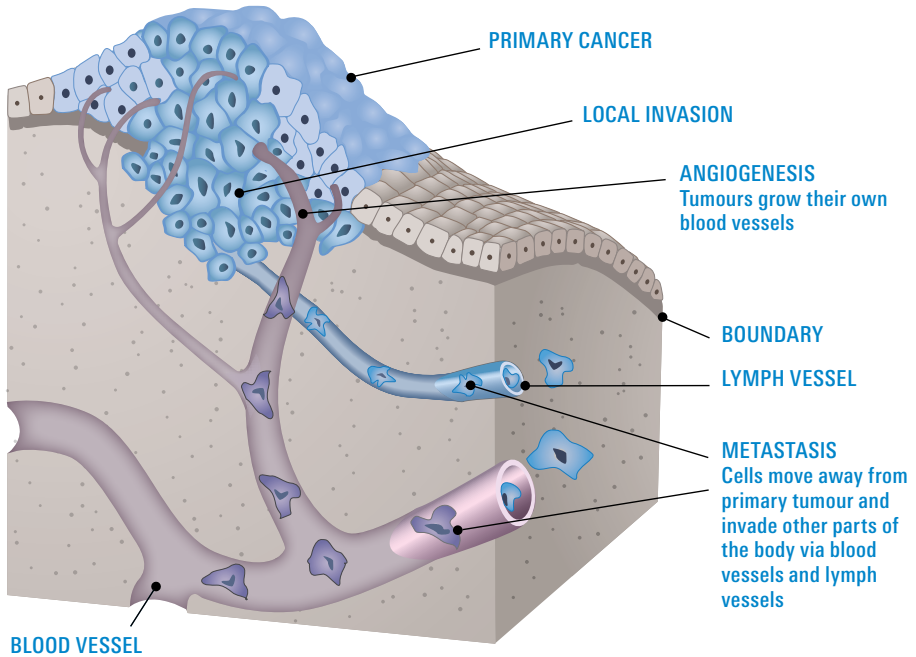
Benign lumps do not spread to other parts of the body.

A malignant lump (more commonly called a malignant **tumour** or a cancer) is made up of cancer cells. When it first develops, this malignant tumour is confined to its original site. If the malignant tumour is not treated, the cancer cells may spread into surrounding **tissue** and to other parts of the body (invasive cancer). When these cells reach a new site they may continue to grow and form another tumour at that site. Such tumours are called secondary cancers or **metastases**.

The beginnings of cancer



How cancer spreads



For a cancer to grow bigger than the head of a pin, it must grow its own blood vessels. This is called **angiogenesis**.

In some cancers, it is the body's blood cells that multiply abnormally. These cancers are called leukaemia, myeloma and lymphoma.

How cancer is treated



Your treatment will depend on the type of cancer you have, where it began, and whether it has spread to other parts of your body. It will also depend on such things as your general health and the type of treatment you choose.

Treatments for cancer include:

- surgery, which aims to remove the cancer cells from your body
- **chemotherapy** and **radiotherapy**, which aim to destroy cancer cells in the body, or at least slow them from multiplying and spreading
- **targeted therapy**, a new form of treatment for some cancers; the therapy mainly attacks just cancer cells
- **immunotherapy**, which helps the body's immune system to fight cancer
- **hormone therapy**, which alters the ability of cancer-growth-promoting hormones to cause some cancers to grow.

People often have more than one of these treatments.

Many cancers can be cured using these treatments, either alone or in combination. When a cure is unlikely, chemotherapy, radiotherapy or other treatments can relieve symptoms, help you feel as comfortable as possible and may make you live longer. This is called **palliative treatment**. This sort of treatment really begins right from the start of your treatment for cancer, since all of the treatments available are intended to improve people's quality of life.

Chemotherapy and why it is used



Chemotherapy is the use of drugs to treat cancer. It works by destroying or slowing the growth of cancer **cells**. Chemotherapy mainly affects fast-growing cells, like cancer cells. Other fast-growing cells can also be affected, like the cells that cause hair to grow.

There are many different types of chemotherapy drugs. Usually, people have several at the same time. But sometimes people have only one drug.

The aim of chemotherapy may be to cure cancer, to relieve symptoms, to help other treatments work better or to improve survival.

Cure

Some cancers can be cured by chemotherapy on its own or combined with other treatments.

Relief of symptoms

Sometimes it is not possible to completely control cancer. However, chemotherapy can often help people feel better. Symptoms such as pain may be relieved if the cancer can be made smaller.

Together with other treatments

Chemotherapy can be used along with another treatment, such as surgery or **radiotherapy**. When the aim of chemotherapy is to prevent a **recurrent cancer**, it is called **adjuvant therapy**. Adjuvant chemotherapy can be given either before or after surgery. When given before an operation, the drugs may make the cancer smaller. When given either before or after an operation, chemotherapy may destroy any cancer cells that have not been found and could cause the cancer to return.

Chemotherapy can also be given at the same time as radiotherapy. In some cases, the combination of chemotherapy with radiation is more effective than either treatment by itself.

To improve survival

Having **adjuvant therapy** might increase the chance of long-term survival. In some circumstances, even if the cancer cannot be cured, having chemotherapy might enable people to live longer.

Doctors and other health professionals you may see

Specialists and other health professionals who care for people having chemotherapy include:

- medical **oncologists**, specialist doctors who prescribe and coordinate the course of treatment
- nurses and general practitioners, who will help you through all stages of your cancer treatment
- dietitians, who will recommend the best diets to follow during and after treatment
- social workers, physiotherapists, psychologists and occupational therapists, who will advise you on support services and help you to get back to normal activities.



How is chemotherapy given?

This will depend on the type of cancer you have and the drugs that are used. Chemotherapy can be given in several ways, such as into a **vein**, by mouth, as an injection, or applied on the skin.

When you have chemotherapy there will often be a period of treatment followed by a break. This is called a cycle of treatment. The number of treatments and their frequency will depend upon the type of cancer and the drugs used. In general, people have chemotherapy over six to 12 months. However, you may have it for shorter or longer periods. Discuss this with your doctor.

Into a vein (intravenous, or IV, treatment)

People usually have chemotherapy drugs through a needle in a **vein** (**intravenously**) during visits to the hospital or a clinic. Alternatively, you may need to stay at the hospital for a day or more (it can be up to a week).

If you have short-term chemotherapy (up to a day's treatment), you will have a thin needle inserted into a vein in your hand or lower arm at the start of each treatment session. The needle will be used to place a small plastic tube ('cannula') into the vein. The needle will be removed and the cannula left in the vein throughout the treatment session. A session may take from a few minutes to a few hours.

If the chemotherapy needs to go continuously for several days, a longer, soft, thin, flexible tube can be put into a large vein, usually in the upper arm or chest. These are called lines (sometimes PICC lines), **catheters** or access devices. They are inserted in an x-ray department (radiology) or operating theatre. The line can remain there as long as it is needed. Drugs can be given and blood samples can be taken through them. A few centimetres of the tubing sit outside the vein and the tube is usually taped to the skin.

Sometimes a catheter is attached to a port. A port is a small, round, plastic or metal disc placed under the skin, usually on the chest wall under the collar bone. The port can be used for as long as it is needed. The port is like a small container that drugs can be injected into.

If your veins are hard to access, a line or port will make it easier to have the chemotherapy and blood tests.

A pump is sometimes used to deliver chemotherapy. This stores the drug and controls how fast it goes into a catheter or port. There are two types of pump. An external pump remains outside the body in a belt holster or bag. This allows you to move around while the pump is being used. An internal pump is placed under the skin during surgery. Pumps allow people to go about their normal activities and allow some people to have their chemotherapy at home. If you are going home with a pump, a nurse will show you how to care for it. They will also discuss what to do in the unlikely event of the pump leaking.

Lines and catheters need to be kept clean to prevent infection or blockage. Your nurse will show you how to do this.

Catheters, lines, ports and pumps cause no pain if they are properly placed and cared for, although if you have one you will be aware of it. It is important to report any pain or discomfort with these devices to your doctor or nurse.

By mouth (orally)

You may take some or all of the chemotherapy by mouth (in tablets or capsules). If you have tablets or capsules to swallow, you will be able to have your chemotherapy at home.

Oral forms of chemotherapy drugs are becoming more widely used. They can be just as effective as **intravenous** drugs. It is very important that you take oral chemotherapy drugs exactly as instructed.

By injection

A needle and syringe may be used to inject the drug into a muscle, into the fluid around the spine, into an artery, into the chest cavity or directly into the cancer or an organ.

On the skin

The drug is applied to the surface of the skin in a cream.

How does chemotherapy work?

Chemotherapy drugs travel around your body and destroy certain **cells**. The cells most affected by chemotherapy are those that multiply rapidly, such as cancer cells. Some normal cells that multiply rapidly (like hair cells or blood cells) may also be affected by chemotherapy. However, normal cells can renew themselves better than cancer cells. The rest periods between chemotherapy treatments allow your normal cells to recover before the next treatment.

No matter which way it is given (such as in a **vein** or by mouth), chemotherapy travels in your blood to reach cancer cells in your body. The rate at which cancer cells are destroyed varies with each type of cancer and the drugs used.

Does having chemotherapy hurt?

Having chemotherapy by mouth, on the skin or by injection is like having other medications by these methods. Having chemotherapy **intravenously** feels, at the start, like having blood taken. Some people feel coolness or another unusual sensation in the area of the needle. Report such feelings to your doctor or nurse. It is not painful unless the drugs cause an irritation. Tell your nurse or doctor if you have any

pain, discomfort or burning sensation during or after treatment with intravenous chemotherapy.

Many people have little or no trouble having the needle put into their hand or lower arm. However, if you have problems for any reason, or if it becomes difficult to insert the needle into a **vein** for each treatment, it may be possible to have a line inserted (see information in the section titled, 'How is chemotherapy given?'). Local **anaesthetic** creams may help. Speak to your doctor or nurse about using local anaesthetic creams.

Chemotherapy can be time-consuming

You will probably spend a lot of time in hospital or a clinic: waiting for the doctor, for blood tests, for the results of blood tests or for your chemotherapy drugs to be made up and given.

People cope in different ways, depending on how well they feel and what their needs are. Reading a book or a magazine, listening to music or talking to a friend can provide distraction. Or you may just want to look around, write in a journal, think or meditate.

At first, it may be scary seeing people who are sick from cancer or treatment. You will get used to this. You will probably find people quite friendly and willing to talk, if that is what you wish.

It may help to ask how long your wait will be. If you need to be finished by a certain time, tell the receptionist, nurse or doctor.

How will I know if the treatment has worked?

After finishing your course of treatment, you will talk with your doctor and have several medical tests and examinations, often called staging tests. These tests will show if the cancer has gone away. If the cancer has gone away, it is great news; however it will be several years before it is considered that your cancer is cured. This is because sometimes cancer can shrink to the point where it is not detected, but it may still

come back in the same place (**recurrent cancer**), or grow in another part of the body.

If you have chemotherapy as a **palliative treatment**, the relief of symptoms may tell you if the treatment has worked, but you will probably also need to have scans after a couple of months to see if the cancer has shrunk. If it has shrunk, then chemotherapy may continue. Your doctor will discuss these results with you.

Side effects of chemotherapy



Contact your doctor or chemotherapy nurses urgently if any of the following occur:

- fever over 38°C (100°F), chills or sweats
- easy bruising or any abnormal bleeding
- persistent or severe vomiting: vomiting so often that you can't keep liquids down, despite taking the medication prescribed to you for vomiting
- severe constipation, diarrhoea (more than three extra bowel actions per day, especially if loose or watery) or pain in your **abdomen**
- a sudden decline in health.

The most important effect of chemotherapy is that it destroys the cancer cells. But it may also cause unwanted side effects. Fortunately, most side effects go away in time, and there are ways to reduce and manage the discomfort they may cause.

Side effects vary considerably. Two people on the same treatment may react quite differently. Some people have no side effects. Reactions can also vary from one period of chemotherapy to the next.

Remember that the type and severity of side effects have nothing to do with the success of your treatment. If you have chosen to have chemotherapy it is best to talk to your doctor before your treatment begins about side effects you should watch out for or report. It is also helpful if you know how the side effects may be managed.

The most common side effects of chemotherapy are fatigue or tiredness, feeling sick (**nausea**) and vomiting, bowel problems, mouth problems, hair loss and scalp problems and effects on the blood. These are discussed in more detail below.

During your treatment, tell your doctor or nurse of any side effects you notice. It may be useful to keep a chemotherapy journal (e.g. see the end of this booklet) while you are having treatment, and write down any side effects you have. If you have a severe side effect, the doctor may suggest a break in your treatment, or change the kind of treatment you are having.

Do not use any medicines or home remedies without talking to your doctor or chemotherapy nurse first. They could change the effect of chemotherapy in your body, making it less effective or making side effects worse. Even things you might think are simple and harmless, like vitamins, herbal supplements or anti-oxidants, can have harmful effects when used with cancer treatments.

Side effects may occur during and after the treatment. Awareness of the possible side effects makes it easier to prepare for and cope with them. The following sections describe the most common side effects.

Fatigue

Fatigue is a common side effect of chemotherapy. The cancer itself can also cause fatigue.

Fatigue can include feeling exhausted, tired, sleepy, drowsy or impatient. If you are fatigued you will lack energy and may have trouble paying attention or concentrating.

Fatigue can appear suddenly and it can be overwhelming. It is not always relieved by rest. It can continue after treatment ends.

Cancer and its treatment can cause **anaemia** (reduced red blood cells), which results in fatigue. Your blood cell counts will be monitored by regular blood tests. If you do develop anaemia, your doctor may recommend a blood transfusion to improve your red blood cell count. This can help reduce fatigue.

Try to plan your day so that you can get the things done that you need to do, without being too rushed. Plan to exercise if you are able to: exercise will help you stay fit and maintain your strength and can reduce fatigue. Try not to push yourself to do more than you can comfortably do. Taking short naps or breaks, eating well and drinking plenty of fluids may help.

Don't be afraid to ask other people for help. Family, friends and neighbours may be glad of the chance to help you with tasks like picking up the kids from school, shopping and mowing the lawn.

★ **The Cancer Council has an information sheet on fatigue. Visit www.cancervic.org.au or telephone 13 11 20 for a copy.**

Nausea and vomiting

Chemotherapy can cause **nausea** (feeling sick).

To try to avoid nausea, before your treatment eat only a light meal (e.g. soup and dry biscuits) and drink as much fluid as possible. After treatment, have regular small drinks rather than large drinks. Drink whatever non-alcoholic fluids you prefer: cordial, juice, soda water, dry ginger and weak tea are refreshing. Ice cubes, icy-poles or jellies are other ways to have fluids.

Anti-nausea medication can help. It will probably be given with your chemotherapy. If nausea is likely, you will be given anti-nausea tablets to take at home. You may be advised to have a tablet at home before

your next treatment. Anti-nausea **suppositories** are sometimes used. These are placed in the rectum (back passage), where they dissolve.

If you're feeling ill, don't eat rich or fatty foods. They may make your nausea worse.

Several anti-nausea medications are available. It may take some time before you find the one that is right for you, but keep trying – nausea and vomiting can be reduced with treatment. Ask your doctor, nurse or pharmacist how you should take your medicines. **Contact your doctor if you still have nausea or vomiting despite taking the medication prescribed for you.**

Bowel problems

Constipation may be avoided if you eat high-fibre foods such as wholegrain bread and pasta, bran, fruit and vegetables. It's important to also drink plenty of fluid. Use a laxative if you need to: ask your doctor or nurse which type you could use. **Enemas and suppositories** for constipation are not advised while you are receiving chemotherapy.

Some anti-nausea medications cause constipation.

Some chemotherapy may cause severe diarrhoea, which can lead to dehydration and serious complications. If you are receiving one of these treatments, your doctor should advise you what to do if diarrhoea develops. It may first be treated with medication at home but if the diarrhoea is severe you may need to be admitted to hospital. **If you have more than three extra bowel actions per day, especially if they are loose or watery or contain blood, contact your doctor for advice.**

Avoid dairy products while you have diarrhoea and increase your intake of fluids to avoid dehydration. After the diarrhoea has cleared up, it is important for you to return to a balanced diet that includes fresh fruits, vegetables and wholegrain cereals.

You should report any problems with severe diarrhoea, severe constipation or stomach pain to your doctor.

Mouth problems

Some chemotherapy drugs can affect the lining of the mouth and sometimes cause mouth ulcers or infections. Some people are more likely to have problems than others. Ask your doctor or nurse whether you need to take extra care.

Good mouth care is important for everyone having chemotherapy. Good mouth care includes:

- flossing your teeth carefully once a day
- brushing your teeth and gums after meals and at bedtime using a fluoride toothpaste and a soft toothbrush – an electric toothbrush is ideal
- rinsing your mouth with water after flossing and brushing.

You may be given special mouthwashes to try to prevent mouth infections such as thrush. Do not use commercial mouthwashes without first asking the doctor. Sometimes they contain alcohol, which can irritate your mouth. A teaspoon of salt in a glass of warm water ('swish and spit') will help to keep your mouth healthy: use at least four times a day.

Try eating warm or cool foods rather than hot foods. Avoid spicy foods. If you have a dry mouth it may help to sip fluids, especially water, or suck on ice chips. Moisten foods with gravies, sauces or butter. It may also help you to chew sugar-free gum or consider a saliva substitute, oral gel or dry mouth toothpaste.

If you notice any change in your mouth or throat, such as ulcers or thickened saliva, or find it difficult to swallow, contact your doctor or chemotherapy nurse.

Discuss any dental problems with your doctor. Before you have any dental treatment, tell your dentist that you are having chemotherapy.

Hair loss and scalp problems

Hair loss or thinning is caused by some drugs that temporarily damage the hair. Many drugs do not cause hair loss.

Some people lose all their hair very quickly, others lose it after several treatments, while others lose only a little hair or no hair at all. When hair loss does occur, it usually starts two to three weeks after treatment begins. Your scalp can be tender before hair loss and while your hair is falling out.

Although the head hair is most often lost, some people also lose some or all of their body hair (e.g. hair on arms or legs and pubic hair). Hair loss caused by chemotherapy is not permanent. Your hair will regrow either during treatment or after you have finished treatment.

If it is expected that you will lose your hair, and you would like a wig, your doctor or nurse will help you. If you want to buy a wig, your nurse or social worker may be able to tell you how to get financial help to do so. Some people find it more comfortable to wear a hat or scarf.

Some chemotherapy drugs make you more likely to get sunburn. Remember to protect your head against sunburn and extreme cold. If your eyelashes fall out, wear glasses or sunglasses to protect your eyes on windy days.

To care for your hair and scalp:

- keep your hair and scalp clean
- use a baby shampoo or another very mild shampoo
- comb or brush your hair gently: use a large comb or a hairbrush with soft bristles
- if possible, use a cotton, polyester or satin pillowcase; nylon may irritate your scalp.

Some people have their hair cut short before or during chemotherapy, so any change is not too dramatic.

Avoid hair perms and dyes, which may increase hair loss. Also avoid daily use of hair dryers and rollers and gels, mousses and hair sprays.

In time you will be able to resume your usual hair care routine. This usually happens over months.

When your hair first grows back it may be a little different. Sometimes it will be curly even though it used to be straight. In time your hair will probably return to what it was like before.

Discuss any concerns with your doctor or nurse.

*** Look Good, Feel Better is a workshop for women and men having chemotherapy or radiotherapy, to manage some of the physical effects of treatment. Telephone 13 11 20.**

Cognitive problems ('chemo brain')

After chemotherapy many people say they find it hard to concentrate, focus and remember things. This is often called 'chemo brain'. It can be very frustrating, especially if you need to concentrate on fine detail, for example in your work or study. People who have always been able to concentrate well may find the changes embarrassing and hard to cope with. It may help to know that 'chemo brain' can happen to anyone who has chemotherapy.

Researchers are trying to discover what causes these memory and concentration problems. It is not clear if these problems are caused by chemotherapy alone. The problems usually get better with time, but it may take a year or more. Some of the following tips may help:

- Use a calendar or daily planner to keep track of tasks, appointments, social commitments, birthdays, etc.
- Make lists of things you have to remember: things you need to do that day, things you need at the shops, even where you parked the car.
- See if 'exercising your brain', for example by reading, crosswords, puzzles, study or doing a hobby helps you to concentrate more.
- Plan your activities so you do things that require more concentration when you are more alert, such as in the morning.

- Get plenty of sleep and exercise. Deep sleep is important for memory and concentration. Exercising every day will help you sleep better.
- If your ‘chemo brain’ affects your study or work, let your supervisor or manager know. See if project deadlines, performance reviews and so on can be rescheduled.

Try to be patient. Talking to others, for example, your partner, manager and colleagues, can help to prevent misunderstanding and frustration.

Effects on the blood

The **bone marrow** acts as the ‘factory’ for making **white blood cells**, **red blood cells** and **platelets**. Its job is to maintain normal levels of blood cells (this is called the blood count) to keep you fit and healthy.

Most types of chemotherapy will affect the bone marrow so that your blood count is reduced. The counts may fall with each treatment. You will have regular blood tests to make sure that your blood cell counts are high enough for your next treatment.

Sometimes, a low blood count causes problems. These are related to the type of blood cell affected.

Infection

Chemotherapy may reduce your **white blood cells**. White blood cells are important for fighting infection. So if your white blood cells are low while having chemotherapy (**neutropenia**), bacteria that normally live in or on the body may multiply and cause a fever. You can’t totally avoid infections, but use common sense and avoid people with obvious coughs and colds.

See your doctor immediately if you are unwell or your temperature is higher than 38°C (100°F).

If you are having chemotherapy in winter, check with your doctor about having a flu injection.

Granulocyte-colony stimulating factor (G-CSF) is a treatment given by injection to some people after chemotherapy. It helps to increase the number and function of a type of white blood cell (called **neutrophils**), which help to protect us against infection. G-CSF is not prescribed for everyone. Check with your doctor if it is an option for you.

★ **The discoveries that make G-CSF treatment possible were made in Melbourne by Professor Donald Metcalf, a research fellow funded by Cancer Council Victoria.**

Bleeding problems

Your **platelets** help the blood to clot. Chemotherapy can cause a fall in the number of platelets (called thrombocytopaenia). This can cause you to bleed for longer than normal or you may bruise easily. You may need a platelet transfusion if your platelets are very low.

Anaemia

Red blood cells carry oxygen to the body's **tissues**. If the red blood cells are low due to chemotherapy, **anaemia** can occur. This can make you feel weak and tired and look pale. You may need a blood transfusion.

How to guard against the effects on the blood

Changing your diet will not stop the blood-lowering effects of chemotherapy, however a well-balanced diet is recommended.

Report any unusual symptoms to your doctor. These may include excessive tiredness, bruising or bleeding easily. **If you have a fever over 38°C (100°F), contact your doctor or nurse immediately, day or night. You should have a thermometer at home to monitor your temperature and know how to use it.**

Let your doctor know if you are in contact with chickenpox. It is sometimes necessary to have an injection to guard against getting chickenpox or **shingles**.

Muscle and nerve effects

Some drugs can cause tingling and loss of feeling in the fingers and/or toes, muscle weakness (particularly in the legs), or a change in hearing or ringing in the ears. If this happens, let your doctor or nurse know before your next treatment. A slight change in your treatment might be necessary.

Fertility

Chemotherapy may have a temporary or permanent effect on **fertility**.

Some women who are still having periods before starting chemotherapy may have irregular periods during chemotherapy. They may become regular again after treatment finishes. For other women, chemotherapy can cause premature **menopause**. This means having to deal with the short-term and long-term effects of menopause. Short-term effects include hot flushes, night sweats and dry skin. Early menopause can also lead to concerns about bone strength, bone mineral density and heart disease. After menopause, women can't have children. It can be difficult to consider menopause, while also dealing with your cancer.

Although the chance of a pregnancy in the future may be reduced following chemotherapy, many women are still able to have children. You may be able to store eggs or part of an ovary for future use before starting chemotherapy: ask your doctor about this. Its success has not been fully established and it is only available in some treatment centres.

In men, chemotherapy may reduce **sperm** production. This reduction in sperm numbers can range from very mild to very severe (where sperm are no longer made) and the effect can be temporary or permanent. Some men may consider having sperm stored before treatment starts for use at a later date if desired.

You should discuss these issues with your doctor before chemotherapy.

Special issues



This section looks at matters that will be of concern to some people having chemotherapy.

Contraception

Despite some chemotherapy drugs decreasing **fertility**, it may still be possible for pregnancy to occur. Because there is a risk that chemotherapy drugs may affect **ova** and **sperm**, and hence the unborn baby, pregnancy is not advised, either for female patients or for the female partners of male patients. It is often recommended that you do not become pregnant or father a child for some months after chemotherapy is completed. This is because the toxic effect of the chemotherapy may still be in your ova or sperm. You must use contraception. Discuss this with your doctor or nurse if necessary. Should pregnancy occur, discuss it with your doctor as soon as possible.

Protecting others from chemotherapy

If you are sexually active, use a condom if you have sex on the days you have chemotherapy and for two days after chemotherapy. This is to

protect your partner from any chemotherapy that may be in your body fluids.

Other people should avoid contact with your urine, faeces or vomit during treatment and for the first three to seven days after each chemotherapy treatment.

It is safe for someone having chemotherapy to handle children and be around pregnant and breast-feeding women.

Diet

It is important to eat a range of foods to keep your diet balanced. Sometimes you may not feel hungry. Try to catch up on days when you are hungry. Eat small meals often or snacks if your appetite is poor.

Be willing to change your meals around. If you happen to feel hungrier at breakfast time, have your main meal then and a light meal (such as breakfast cereal) at a time when you feel less like eating.

A hospital dietitian will be able to help if you have problems with food. More diet tips are also available from the Cancer Council Helpline (13 11 20).

★ **The Cancer Council has information on diet and exercise for people with cancer. Visit www.cancervic.org.au or telephone 13 11 20.**

Fluids

You will need to drink more fluids so that the chemotherapy drugs can be quickly removed from your body once they have done their work. This will help reduce side effects. Your doctor or nurse will tell you if this is necessary. If your drugs are given intravenously, you should drink extra fluid for 24 to 48 hours after treatment. If your drugs are taken by mouth, extra fluid is needed on each day that the drug is taken.

Ask your doctor how much you need to drink. Soups, jellies, icy-poles and fruit, as well as more frequent drinks, will help to give you the extra fluid you need.

Alcohol

A small alcoholic drink before meals can help to stimulate the appetite. However, check with your doctor or pharmacist first as some anti-nausea drugs react badly with alcohol.

Skin care

Take good care of your skin while you have chemotherapy. Your doctor should check any changes in your skin, such as rashes, infections or peeling, or any changes in your nails.

It will help your recovery if you get out and enjoy the fresh air. Having chemotherapy may mean your skin is a little more sensitive to the sun than normal, so protect yourself by avoiding the sun in the middle of the day, wearing a hat and shirt and using a good sunscreen (SPF 30+).

Taking part in a clinical trial

Cancer Council Victoria supports participation in clinical trials. They are the most accurate way to determine the effectiveness of promising new treatments or new ways of combining cancer treatments. Always discuss treatment options with your doctor.

If your doctor suggests taking part in a clinical trial, make sure that you fully understand the reasons for the trial and what it means for you. Before deciding whether or not to join the trial, you may wish to ask your doctor:

- What is the standard (best available) treatment for my cancer if I don't go in the trial?

- Which treatments are being tested and why?
- Which tests are involved?
- What are the possible risks or side effects?
- How long will the trial last?
- Will I need to go into hospital for treatment?
- What will I do if any problems occur while I am in the trial?

If you decide to join a randomised clinical trial, you will have either the best existing treatment or a promising new treatment. You will be allocated at random to receive one treatment or the other. In clinical trials, people's health and progress are carefully monitored.

If you do join a clinical trial, you have the right to withdraw at any time. Doing so will not affect your treatment for cancer.

It is always your decision to take part in a clinical trial. If you do not want to take part, your doctor will discuss the best current treatment choices with you.

The Victorian Cooperative Oncology Group and Clinical Trials Office have developed a clinical trial database to make it easier for people affected by cancer and health professionals to find suitable clinical trials. This database was funded by the Victorian Cancer Agency. Visit www.cancervic.org.au/trials for more about clinical trials for cancer.

Complementary and alternative medicines

It's common for people with cancer to seek out complementary and alternative treatments. Many people feel that it gives them a greater sense of control over their illness, that it's 'natural' and low-risk, or that they just want to try everything that seems promising.

Complementary therapies include massage, meditation and other relaxation methods which are used along with medical treatments.

Alternative therapies are unproven remedies, including some herbal and dietary remedies, which are used instead of medical treatment. Some of these have been tested scientifically and found to be not effective or even to be harmful.

Some complementary therapies are useful in helping people to cope with the challenges of having cancer and cancer treatment. However, some alternative therapies are harmful, especially if:

- you use them instead of medical treatment
- you use herbs or other remedies that make your medical treatment less effective
- you spend a lot of time and money on alternative remedies that simply don't work.

Be aware that a lot of unproven remedies are advertised on the Internet and elsewhere without any control or regulation. Before choosing an alternative remedy, discuss it with your doctor or a cancer nurse at the Cancer Council Helpline. Visit the Cancer Council website www.cancervic.org.au or the US National Center for Complementary and Alternative Medicines nccam.nih.gov. Quackwatch at www.quackwatch.com is also a reliable website.

*** The Cancer Council's booklet on complementary and alternative therapies is useful. Telephone 13 11 20 or visit www.cancervic.org.au for a free copy.**

Seeking support



When you are first told you have cancer, you may feel a range of emotions, such as fear, sadness, depression, anger or frustration. It may be helpful to talk about your feelings with your partner, family members or friends, or with a hospital counsellor, social worker, psychologist or your religious or spiritual adviser.

Sometimes you may find that your friends and family do not know what to say to you. They may have trouble dealing with their feelings too. Some people may feel so uncomfortable that they avoid you. This can make you feel very lonely. You may feel able to approach your friends directly and tell them what you need. You may prefer to ask a close family member or a friend to talk with other people for you.

★ You can telephone the Cancer Council Helpline on 13 11 20, Monday to Friday 8.30 am to 6 pm.

Follow-up care

No matter what type of cancer or treatment you have had, you will need regular check-ups. Your **oncologist** will want to see you when you finish your treatment. After this, some people will be referred back to their original doctor or to another doctor experienced in cancer

treatment, and some will continue to see the **oncologist** for follow-up visits.

If you are worried about any unexpected symptoms, contact your doctor straight away. You don't need to wait until your next appointment.

You can read more about follow-up care for your cancer in the Cancer Council's booklets on particular cancers. Visit www.cancervic.org.au or telephone 13 11 20.

Practical and financial help

A serious illness may cause practical and financial problems. You do not need to face these alone. Apart from offering emotional support, a social worker may be able to suggest useful tips to help. Ask at your hospital, your community health centre, or ring the Cancer Council Helpline.

Many services are available, including:

- financial assistance, which may be available for transport costs to medical appointments, prescription medicines, or through benefits or pensions. Contact the social worker at your hospital.
- home nursing care, which is available through district nursing, or through the local **palliative treatment** service – your doctor or hospital can arrange this.
- meals on wheels, home care services, and aids and appliances, which can make life easier – contact the hospital social worker, occupational therapist or physiotherapist, or your local council.

Wigs

If you lose your hair during chemotherapy, you may want to wear a wig, scarf or hat while it's growing back. You can borrow a wig; some hospitals and cancer care units have wig libraries where wigs are available for a small fee. You can buy a wig, though they can be

expensive. Ask your treating hospital or call the Cancer Council Helpline on 13 11 20 to find out more. Some private health funds cover part of the cost of purchasing wigs – check with your health fund.

Exercise

You will probably find it helpful to stay active and exercise regularly if you can. Exercise can help with fatigue and maintaining weight. The amount and type of exercise you do will depend upon what you are used to and how well you feel. Talk with your doctor about what will be best for you.

Relaxing

Some people find relaxing or meditating helps them to feel better. The hospital social worker or nurse will know whether the hospital runs any programs, or may be able to advise you on programs in your area. Your local community health centre may also be able to help.

★ **For Cancer Council information on relaxing and coping with anxiety, visit www.cancervic.org.au or telephone 13 11 20.**

Sexuality and cancer

Cancer treatment and the emotional effects of cancer may affect people with cancer and their partners in different ways.

Some people may withdraw through feelings of being unable to cope with the effects of treatment on themselves or their partner. Others may feel an increased need for sexual and intimate contact for reassurance. Use of condoms for sexual intercourse and dental dams for oral sex are advised for the first 48 hours post chemotherapy treatment.

You may not wish to be sexually active with your partner but other forms of intimacy may still be important to you. It is important to talk about your feelings with your partner. If you have trouble continuing

with your usual sexual activities, discuss this with your doctor or with a trained counsellor.

Some people can feel sad about going through a cancer diagnosis and treatment without a partner. Sharing these feelings with a counsellor or a trusted friend or family member can make a big difference to how you feel.

*** For Cancer Council information on sexuality and cancer, visit www.cancervic.org.au or telephone 13 11 20.**

Cancer Council Helpline

The Cancer Council Helpline is a confidential service where you can talk about your concerns and needs with cancer nurses for the cost of a local call. They can send you information and can put you in touch with support services in your area. Telephone 13 11 20.

'I think one of the most important things is that although you feel you're on your own, you don't have to do it on your own. You need to ask questions and not try to be too stoic. There's a lot of help available. We have to find out where it is and what sort of help suits us.'

Multilingual Cancer Information Line

The Multilingual Cancer Information Line is a confidential Cancer Council service. You can call and speak to a specially trained nurse with the help of an interpreter for the cost of a local call. It is for people with cancer, and people who are close to them. People who speak any language can use the service. See the inside back cover for details.

Talk to someone who has been there

Getting in touch with other people who have been through a similar experience can be very helpful. There are many ways to contact others for mutual support and to share information.

In these support settings, most people feel they can speak openly, share tips with others, and just be themselves. You will probably find that you feel comfortable talking about your diagnosis and treatment, your relationships with friends and family, and your hopes and fears about the future.

Support services available for patients, carers and family members include:

- Cancer Connect, a telephone peer support program that matches you with a volunteer who has been through a similar cancer experience, and who understands how you're feeling.
- face-to-face support groups, which are often held in community centres or hospitals
- telephone support groups for certain situations or types of cancer, which trained counsellors facilitate
- online discussion forums where people can connect with each other any time – see www.cancerconnections.com.au.

Ask your nurse or social worker to tell you about support groups in your area. Visit www.cancervic.org.au or call the Cancer Council Helpline on 13 11 20 to find out how you can connect with others.

Joining a consumer advocacy group can also be rewarding for people who would like to use their experience to make a difference for others. Visit www.cancervoicesvic.org.au for more information.

'It's good to talk to other people if you're afraid, and try to look at ways to overcome the things you're frightened about.'

Living with Cancer Education Program

The Cancer Council's Living with Cancer Education Program provides information on cancer and ways of coping with it. The program runs over one day or several weeks. Groups are small, with plenty of time for talking. Courses are held at hospitals and community organisations throughout Victoria. Contact your hospital social worker or the Cancer Council Helpline.

Caring for someone with cancer



A carer is anyone, whether family or friend, who is helping to look after someone with cancer. Caring for someone with cancer can be very stressful, particularly when it is someone you care about very much. The person with cancer may be experiencing distressing emotions about their cancer diagnosis, side effects from treatment and mood changes from the effects of drugs.

Look after yourself during this time. Give yourself some time out, enjoy a cup of coffee with a friend, and share your worries and concerns with someone not involved. Make a list of 10 things you like to do and make sure that you do one enjoyable thing each day.

You may have to make many decisions. You will probably have to attend many appointments with doctors, support services and hospitals. Many people have found it helpful to take with them another member of the family or a close friend. It also helps to write down questions before you go, and to take notes during the appointment.

Cancer Support Groups are usually open to patients and carers. A support group can offer the chance to share experiences and ways of coping. There is a range of support services such as home help, meals on wheels and visiting nurses that can help you cope with treatment at

home. These are provided by local councils, the Royal District Nursing Service and the palliative care services.

Call the Cancer Council Helpline on 13 11 20 to:

- be linked with another carer by telephone or via the Internet
- speak with a cancer nurse for further support and information
- be sent a carer's kit so that you can find out about financial assistance and other resources.

*** The Cancer Council has a booklet about caring for someone with cancer. Visit www.cancervic.org.au or telephone 13 11 20 for a copy.**

Your personal chemotherapy record

Your doctor or nurse can help you to complete this record.

Diagnosis date: _____

Cancer type: _____

Stage/Grade: _____

Lymph nodes: _____

Aim of treatment: _____

Current Medication Record

Date commenced	Drug	Dosage	Prescribing doctor	End date

Note: Some herbs and vitamins can interact with chemotherapy so that they don't work as they should, or can cause harm. Please check with your cancer specialist to see if it is safe to take and it won't affect your treatment, reduce the effectiveness of the treatment and/or increase the risk of side effects.

Weekly Chemotherapy Journal

Date/time/cycle	Temperature	Side effects	Severity of side effects (mild, medium, severe)	Advice given
Week 1				
Week 2				
Week 3				
Week 4				
Week 5				
Week 6				
Week 7				

Note: The number of treatments and their frequency will depend on the type of cancer and the drugs used. This table is a guide only and can be adapted to your treatment cycle.

Test Results

Date	Haemoglobin	White cell count	Neutrophils	Platelets	Other

Contacts

Telephone

Ambulance

000

Cancer Care Coordinator

Cancer Connect volunteer

Cancer Council Helpline

13 11 20

Cancer Nurse

Cancer Specialist

Dietitian

Emergency

000

GP

Haematologist

Local Hospital

Palliative Care

Pharmacy

Radiologist

Social Worker

Support Group Contact

Surgeon

Taxi

Appointments

Date	Time	Doctor	Location	Notes

Glossary: what does that word mean?

Many of the words listed here are used in this booklet; others are words you are likely to hear used by doctors and other health professionals who will be working with you.

abdomen The part of the body between the chest and hips. The stomach, liver, bowel, bladder and kidneys are in the abdomen.

adjuvant therapy Treatment which aims to prevent a recurrence of cancer after it has been removed.

angiogenesis When tumours grow their own blood vessels.

anaemia A reduced number of red blood cells, which contain the oxygen-carrying substance haemoglobin. Anaemia causes tiredness and fatigue, breathlessness and paleness.

anaesthetic A drug which is taken to stop a person feeling pain during a medical procedure.

benign Not cancerous. Benign lumps do not spread like cancer.

bone marrow The soft tissue inside bones. Three types of blood cells are made in the bone marrow: white blood cells (including neutrophils), red blood cells and platelets.

catheter A flexible tube inserted into a narrow opening so that fluids can be put into or removed from the body.

cells The 'building blocks' of the body. A human is made of billions of cells, which are adapted for different functions. Cells are able to reproduce themselves exactly, unless they are abnormal or damaged, like cancer cells.

chemotherapy The use of special drugs to treat cancer by destroying cancer cells or slowing their growth.

enema Where fluid is passed into the bowel via the anus to cause a bowel action.

fertility For women, being able to conceive a child. For men, producing sperm that can fertilise an egg.

genes The tiny factors that tell the body's cells how to grow and behave. Each person has a set of many thousands of genes inherited from both parents.

granulocyte-colony stimulating factor (G-CSF) A protein that stimulates the growth and maturation of a type of white blood cell, neutrophils (a type of granulocyte).

hormone therapy Use of hormones to treat illness.

immunotherapy The prevention or treatment of disease using substances that alter the immune system's response. The immune system is the body's natural defence system. It protects against anything it recognises as an 'invader', for example, bacteria, viruses, transplanted organs and tissues, cancer cells and parasites.

intravenous Into a vein. An intravenous drip gives drugs directly into a vein.

malignant Cancerous. A malignant tumour is the same as a cancer. It tends to spread, and eventually causes death if it is not treated.

menopause The end of menstruation (periods). Normally, it occurs around the age of 50, but illness and some medical treatments can cause premature menopause.

metastases Also known as ‘secondaries.’ Tumours or masses of cells that develop when cancer cells break away from the original (primary) cancer and are carried by the lymphatic and blood systems to other parts of the body.

nausea Feeling like you may vomit.

neutropenia An abnormal decrease in the number of neutrophils.

neutrophils A type of white blood cell.

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

ova Eggs released from the ovaries at ovulation, in readiness for fertilisation.

palliative treatment Treatment which aims to promote comfort, relieve symptoms and maximise quality of life, when cure is no longer possible.

platelets Parts of the blood that are important in blood clotting.

radiotherapy The use of radiation, usually x-rays or gamma rays, to destroy cancer cells or injure them so they cannot grow and multiply. Radiotherapy treatment can also harm normal cells, but they are usually able to repair themselves.

recurrent cancer A cancer which grows from cancer cells which evaded treatment. Recurrent cancer may appear up to 20 years after the original cancer was treated, depending on the type of cancer.

red blood cells Blood cells that contain haemoglobin, which carries oxygen in the blood.

shingles A disease in adults caused by the same virus that causes chickenpox in children.

sperm The male sex cell. It is made in the testes.

suppository A small plug of medicine inserted into the rectum.

targeted therapy A new form of cancer treatment. Chemotherapy or radiotherapy affects all cells, but targeted therapy is aimed at proteins on the surface of cancer cells. This means damage to other cells is avoided. Targeted therapy is not available for all types of cancer.

tissue A collection of similar cells.

tumour A new or abnormal growth of tissue on or in the body. Tumours can be benign or malignant.

vein A blood vessel that takes blood towards the heart.

white blood cells The white blood cells play a major role in defending the body against infection.

Index

- adjuvant therapy 8, 43
- alcohol 18, 26
- anaemia 16, 22, 43
- anaesthetic 12, 43
- blood 5, 10, 11, 12, 15, 16, 17, 21, 22, 43, 44, 45, 46
- bone marrow 21, 43
- bowel problems 14, 15, 17
- bruising 14, 22
- Cancer Connect 33, 41
- Cancer Council Helpline 25, 28, 29, 30, 31, 32, 33, 34, 36, 41
- carer 33, 35, 36
- catheter 10, 43
- chickenpox 22, 45
- clinical trials 26, 27
- constipation 14, 17
- contraception 24
- cure 6, 7, 8, 12, 45
- diarrhoea 14, 17
- diet 8, 17, 22, 25, 28
- dietitians 8
- enema 17, 44
- exercise 16, 21, 25, 31
- fatigue 15, 16, 31, 43
- fertility 23, 24, 44
- fever 14, 21, 22
- fluids 16, 17, 18, 25, 43
- general practitioners 8
- hair loss 11, 15, 19, 30
- hormone therapy 6, 44
- immunotherapy 6, 44
- infection 10, 18, 21, 22, 26, 46
- injection 9, 11, 21, 22
- Living with Cancer Education Program 34
- Look Good, Feel Better 20
- menopause 23, 44
- mouth problems 15, 18
- Multilingual Cancer Information Line 1, 32
- nausea 15, 16, 17, 26, 45
- neutropenia 21, 45
- nurses 8, 10, 11, 12, 14, 15, 17, 18, 19, 20, 22, 23, 24, 25, 28, 31, 32, 33, 35, 36, 37
- occupational therapists 8, 30
- oncologist 8, 29, 30, 45
- ova 24, 45
- pain 7, 10, 11, 12, 14, 17, 43
- palliative treatment 6, 13, 30, 45
- physiotherapists 8, 30
- platelets 21, 22, 43, 45
- psychologists 8, 29
- pump 10
- radiotherapy 6, 8, 20, 45, 46
- recurrent cancer 8, 13, 45
- red blood cells 16, 21, 22, 43, 45
- relaxing 27, 31

scalp problems 15, 19
sex 24, 31, 32
shingles 22, 45
social workers 8, 19, 29, 30, 31, 33, 34,
41
sperm 23, 24, 44, 46
support group 33, 35, 41
suppository 17, 46
symptoms 6, 7, 13, 22, 30, 45
targeted therapy 6, 46
tumour 4, 5, 44, 46
vomiting 14, 15, 16, 17
white blood cells 21, 22, 43, 44, 46
wigs 19, 30, 31

Cancer information in other languages

خط معلومات السرطان باللغة العربية

إتصلوا بالخط
للتحدث الى ممرضة عن مرض السرطان
باللغة العربية على لرقم **9209 0160**

Polskojęzyczna Infolinia na Temat Raka

Aby móc porozmawiać z pielęgniarką na temat raka w języku polskim należy dzwonić pod numer **9209 0165**

廣東話癌症信息專線

用廣東話與護士談論癌症
請致電 **9209 0161**

Информационная линия по раковым заболеваниям на русском языкеЕсли вы хотите поговорить по-русски с медсестрой о раковых заболеваниях, то позвоните по номеру **9209 0166**

Ελληνική Γραμμή Πληροφοριών για τον Καρκίνο

Για να μιλήσετε σε μια νοσοκόμα σχετικά με τον καρκίνο στα Ελληνικά, τηλεφωνήστε στο **9209 0162**

Línea telefónica de Información sobre el Cáncer en el Idioma Español

Para hablar con un(una) enfermero(a) en español llame al **9209 0167**

Linea Informazioni sul cancro in italiano

Per parlare del cancro con un infermiere in italiano chiama il **9209 0163**

Đường dây Chỉ dẫn về bệnh Ung thư bằng tiếng Việt

Nói chuyện với y tá về bệnh ung thư bằng tiếng Việt, gọi số **9209 0168**

普通话癌症信息专线

若要用普通话与护士讨论癌症
请电 **9209 0164**

For other languages please call 9209 0169. Tell us which language you speak and an interpreter will help you talk to a nurse. To speak to a nurse in English, call 13 11 20.

INTERNET: For information in a range of languages please visit our multilingual website at: www.cancervic.org.au/other_languages



Cancer Council
Helpline
13 11 20

1 Rathdowne Street
Carlton, Victoria 3053
Facsimile 9635 5270
enquiries@cancervic.org.au

www.cancervic.org.au