

When someone you love has cancer



A guide for
people with
cancer, their
carers, family
and friends

A word of caution. Many people look to the Internet for information on cancer. Although there are some very reputable sites, people should be aware that there is no control over the information presented on the net. Therefore there is also a lot of information that is not credible and may be contrary to accepted medical practice. The Cancer Council WA has a brochure on how to use the Internet wisely.

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Introduction

When someone you love has cancer things can change for everyone - sometimes a little, sometimes a lot. The effect of having a close friend or family member with cancer depends on many things, such as:

- Who has cancer
- What sort of cancer they have and how it is treated
- If you have relatives or close friends nearby who can help
- What sort of support the person with cancer has
- Where the person with cancer goes for treatment - near home or to another city
- How easy it is for the person to talk to you about their cancer
- How comfortable you feel talking about cancer
- Whether your friends understand what's going on and how they help you.

No booklet can answer all your questions. This one was written to help you understand more about cancer, how it is treated and the changes that may be happening in your life. It may also help you understand and deal with feelings you have about cancer and about the person you are close to who has cancer. The glossary at the end of the booklet will help explain words used when talking about cancer.

What is cancer?

Cancer is a word used to describe a group of diseases. Each has its own name (such as lung cancer, breast cancer, leukaemia), its own treatment and its own chances of being cured.

Cancer is a disease of the body's cells. The body is constantly making new cells to replace worn-out ones, to grow, or to heal itself after an injury. Normally cells grow and reproduce themselves in an orderly way. Occasionally, however, some cells reproduce themselves in an uncontrolled way and these abnormal cells may grow into a lump that is called a tumour.

Tumours can be benign (not a cancer) or malignant (a cancer). Benign tumours do not spread to other parts of the body. A malignant tumour is made up of cancer cells. These cells can spread beyond the area where the cancer first developed. If not treated the cancer cells may invade and destroy surrounding tissues.

Sometimes cells break away from the original (primary) cancer and may be carried to other organs. When these cells reach a new site they may continue to grow and form another tumour at that site. This is called a secondary cancer or metastasis.

Cancer Treatment

There are three main kinds of treatment for cancer - surgery, chemotherapy and radiation therapy. These are used to destroy cancer cells. Depending on what type of cancer the person has, he or she could have one kind of treatment or a combination of them.

Treatments for cancer sometimes cause unwanted side effects. Side effects are problems caused by the treatment, not by the cancer itself. This happens because while the cancer treatment is aimed at cancer cells, it can also affect some normal cells temporarily.

Surgery

Surgery involves an operation where all or part of the cancer may be cut out. Sometimes surrounding healthy tissue is also removed to get rid of all the cancer. When people have surgery they usually have to stay in hospital until they are strong enough to come home. When they do come home they may be tired and there may be some activities they should not do for a while, such as heavy work, because the body needs time to heal after surgery.

Chemotherapy

Chemotherapy is the treatment of cancer with special drugs that destroy cancer cells. These drugs go into the bloodstream and are carried to cancer cells wherever they are in the body. Chemotherapy is usually given regularly for several months. Even after the person is in remission the treatments may continue in order to destroy any scattered cancer cells.

Chemotherapy is often given through a needle inserted into a vein, (IV) or by mouth (medicines or pills). Many different drugs are used in chemotherapy. Doctors advise which drug or combinations of drugs to use depending on what type of cancer the person has.

Chemotherapy works mainly on the rapidly dividing cancer cells. But healthy cells, especially those that also divide rapidly, can be harmed as well. This can cause side effects and some people having chemotherapy will have some side effects. Most side effects are temporary and will gradually go away after treatment is stopped. The doctor can explain what side effects chemotherapy is most likely to cause.

Side effects of chemotherapy

Chemotherapy can cause nausea and vomiting, and sometimes make people lose their appetite. It can cause mouth sores on the tongue, gums or inside of the cheeks which also makes it hard to eat. People often lose some weight from these side effects. Nausea and vomiting will usually stop within a day or two after chemotherapy. Mouth sores may last longer and may not even start until one or two weeks after taking certain drugs. Many people with mouth ulcers use special mouth rinses to ease the discomfort.

Temporary hair loss is another common side effect of chemotherapy. Sometimes the hair falls out all at once and other times it slowly thins out. There is no way of knowing whether all the hair will come out or not. Even if it does, it will grow back after treatment has stopped. Some people choose to wear a wig, cap or scarf until their hair grows back.

The bone marrow, the inner part of the bone, makes new blood cells. If chemotherapy affects the bone marrow, it cannot produce as many blood cells as usual. When red blood cells are low, the person may be more tired, pale or irritable than usual.

White blood cells fight infection. When they are low the person is more likely to get infection and may need to stay out of crowded places or away from people who have an illness they could catch like a cold, the flu or chicken pox. Because of this you may need to stay away from them if you get sick.

Platelets, another type of blood cell, help stop bleeding. People who do not have enough platelets may bruise or bleed more easily.

Everyone has ups and downs but moods may be more extreme in a person having some kinds of chemotherapy. Just like others, the person with cancer may be sad or worried about the changes it is bringing to his or her life.

Side effects depend on the drugs but remember that some people have no side effects at all.

Radiation therapy

Radiation therapy uses radiation to stop cancer cells from dividing. Some normal cells close to the cancer site may be damaged but most healthy cells are protected by the special shields that are placed over the patient.

To be sure the radiation is aimed right at the cancer, dye or felt tip markers are used to mark the target area on the skin. These marks stay on until treatments are finished.

Radiation therapy does not hurt. The treatments take only a few minutes and are often given each day over a period of several weeks.

In some cases, radiation is not beamed through a machine but instead a radiation implant is placed temporarily in the body. The person who has this sort of radiation therapy is not radioactive during or after radiation therapy and none of the treatments he or she is getting will hurt other people. However when people have an implant in place, you will not be allowed to get too close to them until it is removed. They will be in the hospital during this short period of time.

Side effects of radiation therapy

Although radiation therapy is not painful, it can cause side effects. The person may be more tired than usual. The skin where radiation is aimed may feel sunburnt and this area will need to be protected from the sun. Other side effects depend on where the radiation is given.

Side effects: what you can do to help

You can help to make side effects a little easier to live with. Just understanding that the cancer patient may feel cross or tired or sick from side effects may help you to be more understanding if this happens. And if the person with cancer is tired or sick but wants company, you can spend time with them doing quiet things - talking, reading, watching television or playing games like checkers.

The most important thing you can do, however, is to remember that the person is still the same person as before, even if he or she looks different or cannot do what they used to. Remember, nearly all side effects will gradually disappear after the treatment is finished.

The effect on other people

Any illness changes the life of family and friends for a while. But most illnesses do not last long and life soon gets back to normal.

When someone has cancer, however, it may be different. He or she may need special medical treatment and may go to the hospital or clinic often. Close friends and family may worry, both for the person who has cancer, and for themselves. Cancer is a serious illness and it can be

scary.

People respond differently. Some people may be afraid or angry that their life has changed. They may not be as easy to talk to as before because they are worried. Some people may go on just as if nothing has happened and they may not seem different at all. This does not mean that they do not care - it is just their way of coping. Talking to each other about how you feel can help you to understand each other better.

It is important to remember that everyone is different.

Some things you should know

- Nothing you did or didn't do causes someone to get cancer
- Nothing you thought or said causes someone to get cancer
- Cancer is not catching - you cannot get it from someone else
- Having cancer does not necessarily mean a person will die from it
- If one member of a family has cancer, that does not mean the other members in the family will get it too. In a small number of families however, risk of cancer can be higher, so speak to your doctor about your risk if you are concerned.
- The way you behave cannot change the fact that someone has cancer or that your family and friends are upset
- It is good for you to continue on with your own life

Cure or remission

Although some people do die from cancer, many do not. More people are living with cancer today than ever before. In many cases, cancer treatment can cause a remission which means there are no more signs or symptoms of the cancer. A remission can last for a long time and sometimes lasts so long that the person is said to be cured. Sometimes, however, the cancer comes back. If this happens, it is called a relapse or

recurrence and treatment then is aimed at obtaining another remission.

Whether a person can be cured of cancer depends on many things and no booklet can tell you exactly what to expect. You may want to talk to the doctor, nurse or social worker at the hospital where your friend or family member goes for treatment. You can get help to understand and live with what is happening.

Remember, a lot of cancer research is being done and progress is always being made in treating cancer.

Learn about cancer

One thing that has helped people to understand what is happening when a friend or family member is diagnosed with cancer, is to learn about the type of cancer that person has and the treatment being undertaken. Both these areas are important to know about because there are more than 100 different types of cancer and the treatment for each type is different. In addition, there may be more than one way of treating any type of cancer and people who have the same type of cancer may not be having the same type of treatment. The Cancer Council Helpline 13 11 20 is a good starting point for more information on cancer.

Treatment will depend on the patient's age, whether or not the cancer has spread to other places in the body and what the doctor believes is best for each patient.

Treatment will usually follow a definite plan. However, even if two people have the same type of cancer and the same treatment, the treatment may not work the same way for both of them. Therefore, if you know or hear of someone who has had the same type of cancer and treatment as the person you are close to, and that person did not do well, it does not mean that your family member or friend is not going to get well. **It is important to remember that each person is different and can react to treatment differently.**

Reading about cancer may also be useful. If you decide to read about cancer, be sure what you read is up-to-date. Cancer treatment is improving so fast that even good information may be out of date in less than five years.

The Internet is a useful source of cancer information but unfortunately you cannot believe everything that you read on the Internet. This is because the Internet is open to anyone who wishes to publish information and there is no regulation of the information or its accuracy. It can be difficult to know if all the information that you find there is reliable and occasionally dangerous advice may be given. The Cancer Council's 'Cancer on the Internet' brochure contains helpful information on how to find reliable cancer information on the Internet and is available from the Cancer Council Helpline 13 11 20.

And remember that just as you are an individual, so is the person in your family who has cancer. His or her experiences will not be exactly like those you read about. If you read something or see something on television or in the movies, do not assume that what happens to the cancer patient in the story will happen to the person you are close to.

If you read something or see something on television or in the movies that you do not understand or you want to talk about, try to find someone you can discuss this with. It often helps to talk things over and share your concerns.

Some questions you may want to ask the doctors or nurses

- What kind of cancer do they have? What is it called?
- Where is the cancer?
- Are they going to get better?
- What kind of treatment are they having? Will they have other kinds of treatment?
- How do they feel when they get the treatment?

- Will the treatment change the way they look?
- Will the treatment or cancer change how they feel and act - will they be weaker or bad tempered or the same as before?
- How often will they go back for treatment? How long will treatment for the cancer last?
- How long will they have to stay for each treatment - a morning, a week? Can I come and visit?
- What is it like where they go to have treatment? Can I come?
- Will they be able to go back to school or work while they are having treatment? Will they be at home?
- Will they have to follow a special diet?
- What can I do to help?

You may have questions of your own. Use the pages at the end of this booklet to write down the questions you would like to ask as well as information you find out in answer to them.

Sometimes you will be able to visit the cancer treatment centre instead of imagining what it is like. You can see the building and equipment and meet the people who work there and sometimes other cancer patients.

If you are unable to visit the hospital where the cancer treatment is being undertaken, you could ask the person with cancer and others who have gone to the hospital to tell you about the people they know - the doctors, nurses, social workers and patients - and describe a typical day. They may be able to draw pictures for you and take photographs. This way they can share their experiences with you and you can learn a little about what it is like for them.

Cancer: what it is like for you?

When someone in your family or a close friend has cancer, it may affect you in many different ways. It can be a lot of things; confusing, scary, lonely and much more. You may find that you have feelings that are hard to understand and sometimes hard to talk about.

Remember, feelings are not 'good' or 'bad'. They are just feelings and are usually perfectly normal and shared by many others. Even if you try to wish them away, to ignore them, or if you feel guilty or ashamed of them, they will still be there.

A good way to handle feelings is to talk about them. Talk to close friends or family. You will be surprised how much better you feel once you have talked about your feelings. You may be able to approach:

- neighbours
- work mates
- hospital social worker/psychologist
- another person involved in treating the person you are close to
- a nurse at the Cancer Council Helpline
- a professional counsellor at the Cancer Counselling Service.

It may be hard to talk about cancer

Sometimes it is not easy to talk about what you feel. Not only is it hard to say what you feel, but the other person may not be ready or able to listen or to be helpful. Some of your questions may be upsetting to others because they do not know how to answer or because your concerns remind them of their own. It is possible that they may not be ready to talk when you are.

They may need more time to sort things out in their own minds before they can talk with you. Some people, no matter how much they love you, do not know how to talk about distressing things with you.

Remember:

- Don't be ashamed or afraid of the way you feel. Others in your situation have felt the same way.
- You will usually feel better if you are able to talk about the situation with someone else. Try and share your feelings with friends and family.
- Learn about cancer and the way it is treated. What we first imagine about cancer is often far worse than what is really happening.
- If you don't understand what is being said about the disease or treatment seek clarification.
- There are many people you can talk to about what is going on for you (see previous page).

The Cancer Council Western Australia

The Cancer Council Western Australia is a non-government, community-supported organisation dedicated to reducing the impact of cancer on Western Australians. As the leading cancer charity in WA, we do this by funding cancer research, educating the community about cancer prevention and providing support for cancer patients, their families and loved ones to improve their quality of life.

The Cancer Council WA offers a comprehensive and professional counselling service for people diagnosed with cancer, their families and friends. Individual, couple and relationship counselling; family child and adolescent counselling; and telephone counselling services are offered by qualified and experienced health professionals. Fees are charged at highly subsidised rates. For further information, or to make an appointment, call 9382 9338. Or contact the Cancer Council Helpline 13 11 20.

The Cancer Council also provides many other services for people affected by cancer, including information sessions, support groups, the Wig Service, Look Good...Feel Better (beauty tips for cancer patients), a patient library and accommodation in Perth for country people coming for treatment.

Other information booklets are also available from the Cancer Council Helpline 13 11 20, including:

- Living with cancer
- Understanding chemotherapy
- Understanding radiation therapy
- Nutrition for people living with cancer
- Cancer on the Internet
- Questions you might like to ask your doctor

Glossary

Benign	A tumour that is not a cancer and is unlikely to spread.
Biopsy	The removal of a sample of tissue from the body, for examination under a microscope, to help diagnose a disease.
Cancer	Over 100 diseases where cells that are not normal grow and divide rapidly. They crowd out and destroy normal cells the body needs. Cancer cells can spread to other parts of the body.
Chemotherapy	Use of particular drugs (cycotoxic drugs) to kill cancer cells or slow down their growth.
Diagnosis	Identifying a disease. A diagnosis is based on tests and doctors' experience and knowledge.
Haematologist	A doctor who is a specialist in the study and treatment of blood disease.
Lump	A thickness under the skin that can be felt by the fingers, either by the person who has it or by a doctor. Lumps can be a sign of cancer but most lumps are not cancerous.
Lymphatic system	The network of vessels that make and store cells that fight infection and carry lymph fluid through the body.
Malignant	A tumour that is a cancer.
Metastasis	Also known as a secondary tumour or cancer. A cancer that has spread from another part of your body.
Oncologist	A doctor who is a specialist in treating people with cancer.

Pathologist	A doctor who is a specialist in the study of cells and tissues removed from the body as well as in making a diagnosis based on the changes disease causes in these cells.
Prognosis	An idea of what might happen in a particular person with cancer.
Radiation therapist	A doctor who is a specialist in using radiation to treat diseases.
Radiation therapy	Treatment of cancer with x-rays or other radioactive material. This treatment can be beamed through a machine or implanted in a body part. Radiation therapy does not make the patient radioactive.
Recurrence/relapse	The return of cancer cells and signs of cancer after a remission.
Remission	The disappearance of cancer symptoms and cells. When this happens to a person, he or she is said to be 'in remission'.
Side effects	Problems caused when cancer treatment affects healthy cells in the body. The most common side effects are hair loss, tiredness, nausea, vomiting and mouth ulcers.
Tissue	A group of cells.
Tumour	Cells that group together and keep growing and crowding out normal cells. A tumour can be benign (not a cancer) or malignant (cancer).

For further information contact:

The Cancer Council

Helpline 13 11 20

statewide for the cost of a local call

Weekdays 8 am - 8 pm

TTY (08) 9381 6562



46 Ventnor Avenue

West Perth WA 6005

Phone: (08) 9212 4333

Fax: (08) 9212 4334

cancerwa.asn.au

*The Cancer Council WA is a non-government,
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