



On the road to recovery

Information for people who have
finished cancer treatment

Practical
and support
information

Cancer Council Helpline

13 11 20



On the road to recovery: Information for people who have finished cancer treatment

A guide for cancer survivors, their families and friends

First published May 2014. © Peter MacCallum Cancer Centre, trading as Australian Cancer Survivorship Centre 2014. ISBN 978-1-925136-12-8

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This information has been created as part of an Australian Government Initiative funded through Cancer Australia and collaboration with the Australian Cancer Survivorship Centre, Peter MacCallum Cancer Centre, Psycho-oncology Co-operative Research Group, and Cancer Council.

Note to reader

Always consult your doctor before beginning any health treatment. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for your doctor's or other health professional's advice. However, you may wish to discuss issues raised in this booklet with them. All care is taken to ensure that the information in this booklet is accurate at the time of publication.



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Introduction

Who is this information for?

This information is for people who have finished treatment for cancer, such as surgery, radiotherapy and/or chemotherapy.

Why have we prepared this information?

While finishing treatment for cancer can be a relief, many people say they also have particular challenges in the weeks, months and even years after treatment is finished. For example, it is common to fear that every ache and pain they have means that the cancer has come back. Many people have ongoing side effects from treatment, particularly tiredness. Feeling anxious, sad and depressed at times are also common.

This booklet has practical information and tips to help you get through any challenges you may have. It tells you where you can get help and support.

How did we create this information?

We created this information after talking with people from [Chinese][Greek] backgrounds who have had cancer. We have put some of the things they said into this booklet and have been guided by them as to what information is most useful. Most of the information in this booklet has been adapted from the Cancer Council's English language booklet 'Living well after cancer'.

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Common feelings after finishing cancer treatment

Many people are surprised at the mixed feelings they have after treatment finishes. It is common to feel both anxious and excited. We have included some of the common feelings people have below:

Feeling alone or a sense of loneliness – You may feel abandoned now that you don't have regular appointments, and that friends and family don't understand or can't offer you the help you need.

Fear that the cancer may return – It is sometimes hard to separate normal aches and pains and the after-effects of treatments from worrying that the cancer has come back. This is a very common concern for many people who have had cancer.

Sadness or depression – It is common to feel sad or down on some days. This is often linked to fatigue after cancer treatment. If you are in a low mood for most of the time, or have lost interest and pleasure in most things for more than two weeks, you may have depression.

“For a few months I felt like I was alone, even though I had my mum, my husband, my kids. It was like, ‘Okay, you're well.’ I felt depressed because of not having that attention. No one from the hospital was ringing. I felt betrayed by them, I felt neglected.”

Low confidence – Some people say they feel less confident and more vulnerable after they have had cancer. Often your body and way of thinking may have changed after having cancer and it can take time to adjust.

Anxiety – It is not unusual to feel anxious or hesitant about planning for the future. This anxiety might be higher just before check-ups, on anniversaries of the cancer being diagnosed, or when you see something about cancer on television for example.

“ You get withdrawn to yourself... I wanted time for myself, for me, for my thoughts. ”

It is normal to have a mixture of feelings, and to have good and bad moments. Sometimes people describe getting cancer, having treatment and recovering as a “rollercoaster ride”.

Some people want to return quickly to their usual routines, while others need time to rest after they finish treatment.

Others say they don't want people to make a fuss about them – they prefer to “just get on with it”.

With time, many people say they learn to appreciate things more and prioritise what is important in their lives.

“ I feel that the sky is more beautiful, and [you] appreciate more when you see others smile. ”

Some people say that having had cancer can help them to look at their lives differently. It may prompt them to make positive changes to their lifestyle, such as travelling, spending more time with family or making healthier choices.

It is important to remember that there is no right or wrong way to feel – just as there is no one right way to cope. Many people say that having cancer changes them. Sometimes it takes time to find a “new normal”. Give yourself time to adjust.



Treatment side-effects

Many people have some side effects after treatment. Whether you get side effects can depend on:

- the type of cancer you had
- how far it has spread (you may hear this called the “stage”)
- the treatment you had.

For some people there may be permanent or late side effects. Late effects are problems that happen a long time after treatment finishes. If you are concerned about a new side effect, talk to your doctor.

The side effects can be both physical and emotional. Some problems go away quickly; others can take weeks, months or even years to improve. Your body will cope with the treatment and recovery in its own way. It is best not to compare yourself to others.

Common side effects include:

- feeling very tired (fatigue)
- pain
- feeling sad or depressed
- low self-esteem and confidence
- swelling in the limbs (lymphoedema)
- menopausal symptoms for women
- difficulty concentrating (sometimes called chemo brain)
- changes in sexuality
- fertility problems
- changes in the way your bladder and bowel work (for example having diarrhoea)

- problems with eating or drinking
- weight loss or gain
- mouth and teeth problems
- bone loss (osteoporosis)
- hair loss or other physical changes
- sleeping difficulties.

If the side effects of having cancer treatment bother you, speak with your local doctor or raise them at your check-up appointments with your specialist. It may help to write down your questions beforehand, and bring a support person with you. Ask for an interpreter at the time of booking the appointment with your specialist so that your support person can concentrate on helping you.

Below are some common side effects people who have finished cancer may have. There are suggestions on how to cope with them.



For further information and support, call Cancer Council on 13 11 20. For information in [Greek] [Cantonese][Mandarin]through an interpreter, phone 13 14 50.

Fatigue

Fatigue is when you feel exhausted and don't have the energy to do day-to-day activities. This is the most common side effect of cancer treatment. Up to a quarter of people have persistent fatigue

after cancer treatment. People who have had Hodgkin lymphoma, breast cancer treated with adjuvant chemotherapy, ovarian cancer and those who have had bone marrow transplants seem to be particularly affected.

Symptoms of fatigue

Fatigue differs from normal tiredness. It often doesn't go away with rest or sleep. Some of the symptoms that may be part of fatigue include:

- a lack of energy – you may want to stay in bed all day
- difficulty sleeping (insomnia)
- finding it hard to get up in the morning
- finding it hard to think clearly or make decisions easily
- feeling anxious or depressed, particularly if fatigue persists
- muscle pain – you may find it hard to walk or climb stairs
- feeling breathless after light activity, such as having a shower or making the bed
- difficulty concentrating, even watching TV or talking to someone
- little or no interest in sex (low libido).

Now that treatment is over, you may think you should be full of energy, but often this isn't the case. Many people say that fatigue has a big effect on their life in the first year after treatment. Most people get their energy back 6–12 months after treatment.

Many people worry fatigue is a sign that the cancer has come back or that it never really went away. This is usually not true.

Managing fatigue

Below are some suggestions to help you cope with fatigue:

- Focus on doing a little bit each day rather than a lot in one go.
- Ask for help. Get a friend or family member to help with housework, school pick-ups, shopping or running errands.
- Plan to do the things that are most important to you at the time of day when you have the most energy.
- Do things slowly so that you don't use too much energy as you go. Leave plenty of time to get to appointments.
- Try activities to help you relax, such as do some gardening, have a long bath or listen to music.
- Say no to things that you don't feel like doing. It's OK not to please others all the time.
- Do some regular light exercise. This can give you more energy and make you feel less tired. A short walk may give you energy without exhausting you. Talk to your health care team about what is OK for you.
- Smoking reduces your energy. If you smoke, talk to your doctor about quitting or call the Quitline on 13 78 48 for the cost of a local call anywhere in Australia. They can arrange an interpreter if you need one.
- Save your energy. Sit down to talk on the phone or do chores, such as cutting up vegetables, ironing or loading the washing machine. Sit down to put wet clothes on hangers. Use a trolley to take them to the clothesline. Leave chairs around the house so that you can sit when you feel tired.
- If you have children, play with them sitting or lying down. Board games, puzzles and drawing are good activities.

- Eat nutritious meals and snacks throughout the day. Prepare these when you have energy so they are available when you don't have energy.
- Go to the shops during quieter times.
- Try to get a good amount of sleep. Avoid or limit day-time naps to just 20-30 minutes. Have a sleep routine so that you go to bed and get up at the same time each day.
- Take rest breaks between activities.

It is important to tell your doctor if:

- you get dizzy
- you feel a loss of balance when walking or getting out of bed or a chair
- you fall or hurt yourself
- your body aches
- you lack energy
- you find it hard to wake up
- you have trouble sleeping
- you have been too tired to get out of bed for 24 hours
- you have any breathing problems
- your fatigue becomes worse
- you feel confused or cannot think clearly.

Pain

Some people have pain after cancer treatment.

Chemotherapy and surgery can injure nerves and cause pain and numbness in certain areas of your body. Your skin may be very sensitive in the area you received radiotherapy; this can last for a few months. Scars from surgery can also hurt for a long time.

Pain can stop you from doing the things you want to do. Controlling the pain may let you return to many of the activities you enjoy. There are usually many ways to manage pain. If your pain lasts for a long time or is there all the time, do something about it straight away, before it gets out of control.

Taking medication regularly and at the right dose is the best way to prevent pain from starting or getting worse. Some people call this “staying on top of the pain”. It may mean you can use lower doses of pain relief than if you wait until the pain gets worse.

Common pain-killing medications

Pain-killing drugs, called analgesics, treat different types and levels of pain.

Mild pain – paracetamol or non-steroidal anti-inflammatory drugs, like ibuprofen or aspirin

Moderate pain – mild opioids such as codeine

Strong pain – opioids such as morphine

Let your doctors know how pain is affecting your day-to-day life, as this helps them plan the best treatment for you. Your

pharmacist may also be able to suggest ways to relieve the pain.

Will I become addicted to pain-killers?

People taking opioids at the levels necessary to relieve pain are not at risk of addiction, unless they have had addiction problems in the past. If you are concerned about becoming dependant on pain killers, talk to your doctor.

Will the pain-killers make me drowsy?

If you take the medication as your doctor prescribes, this is not likely. You may feel drowsy at first, but this usually wears off within a couple of days. If it doesn't, talk to your doctor. He or she may need to adjust your dose.

Other methods of pain relief

- Physiotherapy or occupational therapy can help with physical or practical problems that are making you uncomfortable.
- Complementary therapies such as acupuncture, massage and reflexology can help with well-being, getting control over pain, improving your mood, and lowering your stress and anxiety.
- Deep breathing, meditation or listening to your favourite music may help you sleep at night, give you more energy, reduce anxiety and make other pain-relief methods work better.
- Applying hot or cold packs to affected areas may provide relief.
- Focusing your attention on something other than the pain. For example, you can listen to music or do something creative, such as paint a picture.
- Surgery or nerve blocking (an anaesthetic injected where the pain is).



If you would like more information and support to cope with your pain, contact the Cancer Council on 13 11 20. For information in [Cantonese][Greek][Mandarin] through an interpreter, phone 13 14 50.

Feeling sad or depressed

Many people feel sad or low after cancer treatment. Don't be surprised if you feel unhappy at times. You may worry about the changes to your appearance, feel anxious about planning for the future, or worry about your health. It is natural to feel worried or sad some of the time.

But there is a difference between feeling unhappy and being depressed. You may be depressed if you are in a low mood for most of the time, or have lost interest and pleasure in most things for more than two weeks. Depression often won't go away by itself. Tackling it early may mean that you can deal with problems quickly and avoid symptoms becoming worse. Sometimes it may be hard to work out if you have fatigue or depression. Speak to your doctor if you are concerned about your symptoms. There are also many treatments for depression, such as medication and counselling.

Finding a counsellor who speaks your language

Many people say that speaking with a counsellor in their language helps. If you or someone you know uses the internet, you can search for a counsellor in your own language through the Australian Psychological Society. Visit their website at www.psychology.org.au > community information > find a psychologist. Use the advanced search tab to specify your preferred language.

You may be able to get some, or all, of the cost of speaking with a counsellor back through Medicare. Help to pay for up to ten counselling sessions is available through a GP Mental Health Plan. Speak to your local doctor about this.

Look Good...Feel Better program

This free program teaches ways to help with how you look and self-esteem. It is for people having cancer treatment, but may also be available to people who have recently completed treatment. For more information and to learn if you are eligible for the program, call 1800 650 960 or visit www.lgfb.org.au

tips

For mental wellbeing

- Take care of yourself, eat a well-balanced diet and drink plenty of water.
- Set small goals that you can achieve. Don't expect too much from yourself.
- Get regular exercise. Studies have shown that being active helps lift a person's mood and gives you more energy.
- Share your feelings with someone close to you, this may help you feel less alone.
- Go out and do something you enjoy. Doing something different can often make you feel better. Spend time outside in the fresh air. Schedule a pleasant event or daily activity.
- Think about what is important to you, try not to judge yourself too harshly.
- List activities you used to enjoy and plan to do one of these activities each day.
- Write down how you're feeling or express yourself in painting, drawing, music or singing.
- Try massage, yoga, hypnosis, acupuncture or reflexology.

Lymphoedema

Lymphoedema is swelling from a build-up of lymph fluid. Lymph glands are glands found all around the body, including the armpit, groin, stomach, chest and neck. Usually the swelling occurs in a limb, such as your arm, particularly for women after surgery for breast cancer.

Lymphoedema can take months or years to happen, though some people never get it.

Improvements can be slow and this condition tends to happen again or linger. A physiotherapist or lymphoedema specialist can fit you for a pressure garment and give massage to help with symptoms.



It is important to prevent infection in the affected area and to keep the skin moisturised. Avoid:

- sunburn
- cuts, burns and insect bites
- using blood pressure cuffs
- having injections.

Menopause

Menopause means a woman's ovaries no longer produce eggs and her periods stop. When this happens, it means she can no longer have children. The average age for a woman to get natural menopause is 52.

Menopause after treatment for cancer may be for a short while, or forever. Either way, you may have menopausal symptoms. Cancer treatments that can cause menopause include:

- some chemotherapy drugs
- radiotherapy to the pelvic area (below the hips)
- hormone treatment
- surgery to remove the ovaries.

For women who want children, menopause can be devastating as it means they can no longer have children. Even if your family is complete or you didn't want children, you may have mixed emotions and worry about how it will affect your relationship. Some women find menopause difficult because they feel it has taken away a part of their identity as a woman.

Symptoms

While natural menopause can be a difficult time for a woman, it may be more difficult if menopause happens suddenly because of cancer treatment.

Symptoms may be severe because the body hasn't had time to get used to the hormones going down gradually.

You may get:

- hot flushes
- mood swings
- trouble sleeping
- tiredness
- vaginal dryness.

Many of these symptoms will pass with time, though it can take months or a few years. You are also at risk of getting weak and brittle bones (osteoporosis). Ask your doctor what to do about this.

What to do about menopause symptoms

- Hormone replacement therapy (HRT) can help reduce symptoms. However, this may not be recommended, especially in women who have had hormone-sensitive breast cancer.
- Eat a healthy diet with lots of fresh fruits and vegetables, and wholegrains. Ask your doctor if you want advice about changing your diet or taking herbal remedies.
- Talk to your doctor about medicines without hormones that might help with symptoms such as hot flushes.
- Extra lubrication for the vaginal area may make intercourse more comfortable. Choose a water or silicone-based gel without perfumes or colouring (e.g. Sylk® or Pjur®).
- Use oestrogen in creams or pessaries to help with vaginal dryness. Moisturisers without oestrogen can also be used.
- Take more time before and during intercourse to help the vagina relax and become more lubricated.

Men who are taking hormone treatment or have had their testicles removed may also have symptoms such as feeling hot, sweaty and tired. If you have these symptoms, ask your doctor about what can help.

Problems concentrating, focusing and remembering things

After treatment, many people say they have difficulty concentrating, focusing and remembering things. This usually happens after chemotherapy, so some people call it chemo brain. However, other treatments (e.g. hormone therapy and radiotherapy) and side effects, such as fatigue or depression, can also affect how well you can think and concentrate.

This problem usually improves, but it may take a year or more.

tips

To help you manage:

- Use your mobile phone, a calendar or daily planner to keep track of tasks, appointments, social commitments, birthdays etc.
- Plan your activities so you do things that require more concentration when you are more alert, e.g. mornings.
- Set calls to go to voicemail. Put aside time each day to answer calls and emails.
- If you are working and have your own office, close the door when you don't want to be interrupted.
- Put personal items (e.g. wallet, keys) in the same place at home and at work so you don't misplace them.
- Make notes of things you have to remember, e.g. a shopping list or where you parked the car.
- Do things one at a time rather than trying to do many things at once.
- Get plenty of sleep and exercise. Deep sleep is important for memory and concentration. Getting some physical activity everyday will help you sleep better.



Fear of the cancer coming back

It is very common to worry about whether the cancer will go away, or come back later. For some, this may affect their ability to enjoy life or make plans for the future. For some people these fears are so strong that day-to-day life can become a big struggle. They don't find many pleasures in life or believe they will ever enjoy life again. Some people describe the fear as “living with a shadow over you”, or “having a monkey running around in your head”.

This concern may be worse at certain times such as on special occasions, before follow-up appointments, and on hearing about other people diagnosed with cancer.

By acknowledging fears, and taking control of them, many people find they can enjoy life again. Many find the fear of the cancer coming back lessens with time.

“ I keep thinking that I have something on a different body part. And that's the worst thing. Because you don't know. ”

Will the cancer come back?

You may wonder how likely it is that the cancer will come back or how long people with your type of cancer live. You need to discuss your case with your doctor. He or she can give you an idea of what may happen to you or tell you the most recent survival statistics (see opposite page). This is a general guide and there is always some uncertainty. Many people say it is frustrating not getting a

definite answer. The chance of the cancer coming back is different for each person. It depends on many factors including:

- the type of cancer
- how far it has spread
- the treatment you had
- the time since treatment.

Generally, the more time that goes by, the less likely it is that the cancer will come back.

Survival statistics

Doctors generally avoid the term “cure”, even if it looks like the cancer is not likely to return. Instead, they may use the term “five-year survival rate”. This is because research studies often follow people for five years. The information we have about the number of people alive after five years is often used to predict the chances of the cancer coming back.

Five-year survival rate means the percentage of people alive five years after they get cancer. For example, about 94 out of every 100

“Of course we are worried about recurrence. But the doctor will say you have recovered and that you are a normal person now. It is impossible! It is a long-term disease. But for the doctor, you will recover after the surgery. But we still have concerns.”

people (94%) that get thyroid cancer will be alive five years after they are diagnosed. Five-year survival does not mean you will only live five years. Many people live much longer than five years after diagnosis. Not everyone wants to find out about these statistics. Don't feel you have to find out, even if those around you want to know. Do what feels right for you.

Ways to manage the fear

- Talk to a medical professional about your risk of the cancer coming back.
- Focus on what you can control, e.g. being involved in your follow-up appointments and making changes to your lifestyle.
- Recognise the signs of stress, such as a racing heartbeat or sleeplessness, and try to manage this in a healthy way. For example, doing some meditation or light exercise might help.
- Join a support group or speak with a Cancer Council volunteer who has been through similar things to discuss your concerns. Phone 13 11 20. For information in [Cantonese][Greek] [Mandarin] through an interpreter, phone 13 14 50.
- Speak to a counsellor if the fear of the cancer coming back is overwhelming or if it is affecting your relationships. The counsellor may be able to help you think in a more positive way.
- You can find more information in [Cantonese][Greek] [Mandarin] about ways to manage anxiety and depression at Beyond Blue (1300 224 636) or visit their website at www.beyondblue.org.au

Checking for signs of a new cancer

At first, you may worry that every ache, pain or feeling of sickness might mean that your cancer has come back. Try to remember that every symptom doesn't mean your cancer has come back. Everyone has aches and pains, coughs and colds. However, it is important to contact your doctor if you have concerns, if you feel that something is wrong or have symptoms that are new or different.

●● After you feel pain you will think, 'what if the cancer cells spread to this area?' ●●

General warning signs of cancer may be:

- a lump anywhere in your body that doesn't go away
- a mole or skin spot that changes shape, size or colour
- a cough or hoarseness that won't go away
- changes in bowel habits (e.g. diarrhoea or constipation for more than six weeks)
- abnormal bleeding
- weight loss that you can't explain
- fatigue that you can't explain.

Ask your doctor about what symptoms to look out for that might suggest that the cancer might have returned.



Follow-up care

After your treatment has finished, you may need regular check-ups so that your doctor can check your health and well-being. How often you see your specialist depends on the type of cancer and treatment you had, plus any side effects-you are experiencing. It is usually different for each person. With some cancers, there is no evidence that regular follow up tests lead to better survival. If you have any questions about why you are having particular tests, or no tests at all, discuss these with your doctor.

Your treatment summary

It's a good idea to ask your oncologist or other cancer specialist for a written summary of your cancer type, treatment and follow-up care.

Share this summary with your GP or any new health care providers you see. It helps guide them for your care when you've finished treatment.

This summary should include the following:

- type of cancer
- date of diagnosis
- diagnostic tests performed and results
- pathology results: how far the cancer has spread, its grade,
- the hormonal status (usually for people with breast cancer), and Information about any blood tests that might suggest cancer in the body
- treatment details (e.g. type of surgeries, where and how

What do check-ups involve?

During check-ups your doctor will:

- see how you're recovering
- ask how you're feeling and coping with life after cancer
- monitor and treat any ongoing side effects
- look for any signs that the cancer may be coming back
- investigate any new symptoms
- ask if you have any concerns
- discuss your general health and suggest things you can do to keep yourself healthy, such as diet and exercise.

Blood tests and scans may be taken, depending on the cancer type and treatment. For example, women treated for breast cancer need mammograms and men treated for prostate cancer need PSA tests. You may not need tests. In some circumstances, research studies have shown that doing regular tests does not help find cancer. The tests are not always accurate and they can have side effects.

much radiation therapy you had, names and doses of chemotherapy and all other drugs, results of scans and x-rays)

- list of symptoms to watch for and possible long-term side

effects of treatment

- contact information for health professionals involved in your treatment and follow-up care.

Being honest with your doctors will help them manage any symptoms that are bothering you. For instance, you should let them know if you feel very low in mood or energy. It is also important to let them know if you are using any other therapies, such as taking herbs or vitamins, on a special diet or having acupuncture for example.

It is important to ask your doctor questions about anything you do not understand. Sometimes this can be hard. Doctors can be very busy, and sometimes you may not know which questions to ask. It can help to write down questions before your visit. It is a good idea to take someone with you to your appointments. They can ask questions or write notes about what the doctor says.

How often do I need check-ups?

How often you have check-ups depends on the type of cancer you have.

Some people have check-ups every 3–6 months for the first few years after treatment, then less frequently thereafter. Talk to your doctors about what to expect. Sometimes your GP (local doctor) can do the follow-up. Your GP will be important to manage any other issues anyway.

“ I wanted the doctor or professor to help me. I wanted more frequent contact. I wanted to ask questions and get answers. ”

If you need reassurance, you can visit your GP in between visits to talk about any concerns.

It may help to find and go to the same GP that you are happy with, rather than going to many different ones. In this way, your GP will be across your overall health and will be aware of your history. It may also help to book a longer consultation so that you do not feel rushed. Your GP will also be able to refer you to some health services that are free, or come at very little cost to you. These can help with your care after cancer, including seeing a physiotherapist, optometrist, psychologist, dietitian etc.



Family & friends

How family and friends may feel after treatment ends

People close to you can have a range of reactions when your cancer treatment ends. They may feel:

- relieved that you're okay
- happy to focus on others and themselves
- exhausted
- confused, especially if your relationship has changed
- pleased they can catch up with family and friends without cancer dominating the conversation
- worried about what the future holds.

“ Even though they do not say it out aloud, you know they are anxious and worrying about you. ”

After treatment is over, your family and friends may also need time to adjust. Carers often have high levels of distress, even when treatment has finished. Like you, they may be worried about the cancer coming back. Let your family and friends know that you understand it is hard for them as well. Tell them how much you appreciate all they have already done to help you. Let them know if you still need their support. Often people say they do not want to worry their family by talking about their fears, or asking for more help. It may be confronting to lose some of your independence, but keep in mind that this is likely to be temporary. It is important to talk about what you need and listen to what your family says too.

Communicating with family and friends

When treatment finishes, your family and friends may expect you to act the same as before the cancer. If you have changed, people close to you may be disappointed, worried or frustrated. Friends and family may say things like “but you look fine”, “your treatment has finished now” and “the cancer has gone, hasn’t it?”. They may have difficulty accepting that some symptoms, such as tiredness, may persist for long periods of time. You may feel you’re expected to be grateful you’re still alive, no matter the side effects. It’s natural for family and friends to want the distress and disruption of cancer to be behind you. They care for you and want you to be well.

👂👂 The (family) should be patient, help with chores and they shouldn’t react badly if you are sad or angry. That’s the only way to help you get over it. 🗣️🗣️

However, if you find their reactions difficult to handle, you might need to talk to them about how you’re feeling. You may need to tell them that your recovery is ongoing, and you need time to think about what you’ve been through. You might not be able to just “get on with it” as quickly as they might want you to.

Many people have found it helps to share their feelings with a volunteer who has been through it, or to join a support group. Sometimes there are volunteers and support groups in your language. Contact the Cancer Council on 13 11 20. For information in [Cantonese][Greek][Mandarin] through an interpreter, phone 13 14 50. A list of support groups in [Cantonese][Greek][Mandarin] is available at the back of this booklet.



Some people in your community may avoid seeing you or talking about the cancer. This may be because they are scared, or think that the cancer is contagious. Cancer is not contagious.

“ I have a friend who had her operation five years ago and when she’s approaching another woman to kiss her hello, the other woman backs away to avoid it. ”

Will my family inherit my cancer?

If you’ve had cancer, it doesn’t automatically mean that your children will get it too.

If you are concerned the cancer is inherited (for example if you have two or more close relatives on one side of the family who have had cancer) talk to your doctor about whether your family needs regular screening.

Your doctor may also refer you to a family cancer clinic or to a genetic counselling service. Here they will:

- ask you about other people in your family who have had cancer
- talk about the chances of it running in the family
- speak with you about what you can do next.



Money matters

Cancer treatment can be expensive. Stopping work, paying for treatment, buying medications and travelling to treatment may leave some people with financial problems. It can help to speak with the hospital social worker before treatment finishes. He or she can give you advice to help with some of these concerns.

Financial hardship

If you're struggling with debts, ask your lender (for example, your bank) if they can consider your situation.

If you are on a low income or unable to work because you have had cancer, you may be able to get payments. Talk to Centrelink as early as possible as there may be waiting periods. Visit the Centrelink website at www.humanservices.gov.au > Centrelink (select the tab at the top of the page for your language) or phone 13 12 02 to speak to someone in your language.

You can also see a financial adviser – visit www.financialcounsellingaustralia.org.au to find a counsellor in your area.

Cancer Council 13 11 20 has more information and some services to help people having financial difficulties. For information in (Greek/ Cantonese/Mandarin) through an interpreter, phone 13 14 50.



Insurance

Applying for new insurance (for example, life, income cover, mortgage or travel) may be harder because you have had cancer. You will need to provide your medical history for many insurance policies and insurers may vary the terms and conditions, or charge higher premiums, based on a history of cancer.

You should be able to claim on policies you had before diagnosis. You will need to tell your insurance company that you have been diagnosed with cancer.

It may be difficult to get travel insurance that covers medical problems related to the cancer, but you should be able to get a policy to cover basics such as lost baggage, theft and cancelled flights. It is best to shop around and read the conditions of each policy carefully.

Superannuation

While generally you are unable to access your superannuation before retirement age, there are some circumstances under which you can access your superannuation benefits at any age. These include:

- severe financial hardship
- specific compassionate grounds
- permanent incapacity
- a terminal medical condition.

If you are having difficulty meeting your expenses and would like to look into getting your superannuation benefits early, you can

contact your superannuation fund to talk about this. Some super funds also include disability and death benefits, to which you may be entitled.



Working after treatment ends

Work is an important part of life for many people. Besides income, it can provide satisfaction and a chance to socialise. If you took time off work for treatment, you may choose to return to work or get a new job when you have recovered. Some people need to do this because of income and family needs.

Your rights and responsibilities

Q: Do I have a right to return to my job?

A: Australian laws require an employer to take reasonable steps to accommodate the effects of an employee's illness, for example, by giving you a supported chair or moving your workstation to the ground floor.

If you are unable to carry out your previous role, your employer may offer a rehabilitation scheme to train you for another role. Your employer doesn't have to offer you a different job unless your cancer is work-related.

Q: Do I need to say I had cancer when applying for a new position?

A: While some people want to mention their cancer when they apply for a job, you don't have to tell a potential employer unless it is relevant to the position. If you'd prefer not to, and are asked about a gap in your work record, you might want to say that you had a health issue and it's now resolved.

A prospective employer can ask you about your ability to

perform tasks that are an essential to the job you are doing, for example, lifting heavy boxes. If something is a problem for you because of the cancer or treatment, it's best to mention it at the interview.

Q: What if I can no longer work?

A: If treatment has made it impossible to return to your previous work, then rehabilitation and retraining programs can prepare you for another job. Your employer may have a rehabilitation scheme.

Q: Where can I get more information?

A: Cancer Council has more detailed information about employment and cancer. Visit www.cancercouncil.com.au to download a free copy of *Cancer, Work and You*. This resource is in English.

Discrimination at work

Some people are treated differently at work after a cancer diagnosis. Employers and colleagues may doubt your ability to work, or think you need more time off. Anyone who has had cancer is protected by the Disability Discrimination Act.

This prevents employers from discriminating against people with disabilities in the workplace. If you need advice, you could speak to a social worker or solicitor with an interpreter present. They can refer you to the right body who can deal with your concern.



Practical & social support

Volunteers and support groups

Many people say that speaking with others who have had cancer gives them hope, encouragement and information. Many also say that going to a support group, or speaking with a volunteer who has had cancer, can help.

“ They introduced me to someone who suffered the same illness as me... he gave me such encouragement, boosted my confidence. ”

The Cancer Council has:

- nurses who can speak with you through a phone interpreter
- volunteers who have had cancer and who speak other languages
- information on support groups near you.

These services are all free. Phone the Cancer Council on 13 11 20. For information in [Cantonese][Greek][Mandarin] through an interpreter, phone 13 14 50.

There are various cancer support groups run in [Cantonese] [Greek][Mandarin]. If there is a group in your state, you will find it at the back of this booklet.

Home help and childcare

There is no shame in speaking about what you need, and asking for help from family and friends. You may need help with housework or looking after young children for example. The chance to help you can make your loved ones feel as if they are being useful.

Your local Council may also help with house cleaning, gardening and child care. Contact them for more information. You can usually find their number on your rates notice or by looking them up in your local directory or on the internet.

“ My doctor had to sign a form stating my situation and then I would be able to go to the Council to ask for help... I know some women who have home help every time, once a week. ”



Staying healthy

Many people are concerned about diet and exercise after cancer treatment. Are there particular foods they should avoid? Are there foods they should eat more of?

There are no particular foods that you should avoid or have in excessive amounts.

Many people (including your friends and family) will often turn to the internet for answers about diet. It is important to remember that there is no single superfood that has been shown to prevent cancer. In the same way, there is no single food that has been shown to cause cancer. Be wary of advice that tells you to eliminate many types of food or whole food groups from your diet.

It can be frustrating when your doctor does not give you specific advice about diet. Research does suggest that a healthy lifestyle in general can stop or slow the growth of many cancers (in combination with conventional treatment). It also shows that some people who have had cancer may have a higher chance of getting other health problems, such as heart disease, lung problems or diabetes. While more research needs to be done, the lifestyle changes recommended for cancer prevention may also help lower the chance of the cancer coming back or a new cancer growing. They can also prevent other health problems.

Some of the key things you can consider:

Maintain a healthy body weight

A healthy body weight is important for lowering the chance of the cancer coming back. It can also improve survival. There are different techniques to measure a healthy body weight. The simplest way is to measure around your waist (waist circumference).

Waist circumference and health risk

Having fat around the abdomen or a potbelly, regardless of your body size, means you are more likely to get conditions such as diabetes, heart attacks and certain types of cancers. Fat around the hips and buttocks doesn't appear to have the same risk. Men, in particular, often put on weight around their waist.

If you have lost a lot of weight during treatment, you may have to regain some weight to return to a healthy weight. If you are very malnourished and are struggling to put on weight, it may help to visit a dietitian. If you are eligible, your local doctor can refer you to see a dietitian for free or at reduced cost.

Waist circumference	
Men	Women
94 cm or more – increased risk	80 cm or more – increased risk
102 cm or more – substantially increased risk	88 cm or more – substantially increased risk

tips

Losing weight

- Make fruit and vegetables, wholegrain breads, cereals, pasta and rice and other low fat foods the basis of your diet.
- Choose lean cuts of meat and trim as much fat as possible before cooking.
- Limit your intake of red meat and processed meat, such as sausages.
- Remove the skin from chicken.
- Cook food in ways that use less fat – grill, steam, poach or bake.
- Use a non-stick frypan or a spray of oil when pan-frying.
- Try low-fat varieties of milk, yoghurt and cheese.

tips

Gaining weight

- Eat several small, frequent snacks throughout the day, rather than three large meals.
- Eat your favourite foods at any time of the day. For example, eat breakfast foods for dinner if they appeal to you.
- Eat every few hours. Don't wait until you feel hungry.
- Eat your biggest meal when you feel hungriest. For example, if you are most hungry in the morning, make breakfast your biggest meal.
- Try to eat high-energy, high-protein foods at each meal and at snack times.
- Exercise lightly or take a walk

- Don't use butter or margarine, or use only a scrape.
- Limit the number of high-fat takeaways. For instance, avoid foods with a lot of coconut milk and fried foods.
- Avoid high-fat snacks such as crisps and biscuits.
- Have smaller portions.
- Eat slowly and listen to your body – only eat when you're hungry and stop eating when you're full.
- Try to eat at least two serves of fruit and five serves of vegetables each day.

before meals to increase your appetite.

- Drink high-energy, high-protein drinks like milk shakes and canned liquid supplements.
- Drink most of your fluids between meals instead of with meals. Drinking fluid with

meals can make you feel too full.

- Try homemade or commercially prepared nutrition bars and puddings.

Dietary supplements (vitamins & herbs)

People who have survived cancer often consider taking vitamins and herbs. You may find that your family give you lots of information and suggestions about dietary supplements that they find on the internet. This could include things like eating almond kernels, shark cartilage, drinking only juices etc. Often these things can be very expensive. In most instances, the claims they make cannot be proven and sometimes they can make you sick.

Some believe that high-dose vitamin supplements strengthen the body's immune system. However, there is little scientific evidence to support these claims. Some studies show that in high amounts, vitamin supplements may be harmful.

Dietary supplements should never replace whole foods like fruit and vegetables, which are the best source of vitamins and minerals. Even if you feel worried or embarrassed, discuss plans to take vitamins, herbs and other dietary supplements with your doctor or dietitian. They can give you information about whether these things are safe, and if they will affect any treatments you have had. Doctors are used to such questions. It is in your interest to tell them about any other herbs or natural medicines you are taking.

Quit smoking

If you are a smoker, Cancer Council strongly recommends that you quit. There is no safe level of tobacco use. Tobacco smoke contains more than 7000 chemicals, including 69 known cancer-causing agents (carcinogens). Research shows that smoking makes the chance of

cancer coming back higher. Also, by continuing to smoke you are more likely to get another type of cancer. Many smokers find quitting difficult. Don't be discouraged if it takes several attempts before you are able to quit successfully. Call Quitline on 13 QUIT (13 78 48) to talk confidentially to a quitting advisor and request a free Quit Pack. They can arrange an interpreter if you need one. You can call them for the cost of a local call anywhere in Australia

Be physically active

Physical activity helps to protect against some types of cancer coming back. Exercise can also help:

- give you more energy
- lower fatigue
- build your strength
- relieve stress
- reduce heart disease
- lower anxiety and depression.

If you are unsure about whether you are well enough to exercise or if it will interfere with your recovery, talk to your doctor first. It may be hard getting started, particularly if you are fatigued after cancer treatments.

Start activity slowly and do more gradually. Every person is different. The amount and type of activities will vary. Doctors usually recommend about 20–30 minutes a day of moderate physical activity. It may help to start with 5-10 minutes and work up from there.

tips

Increasing activity

- Walking is great exercise. Walk with a friend or join a walking group, walk to the corner shop instead of driving, or try walking in the water instead of swimming.
- Do activities such as Taichi, Qi Gong, Guo Lin Qi Gong.
- Do some gardening.
- Do some simple stretching exercises while watching television.
- Take the stairs instead of the lift or escalators.
- Do energetic housework such as vacuuming or mowing the lawn.
- Get off the bus or train one stop earlier or park further away from your destination and walk the rest of the way.
- Take your children or grandchildren to the park or kick a ball around the backyard.

Limit or avoid alcohol

Alcohol is a risk factor for some cancers, particularly cancer of the mouth, throat, oesophagus, bowel (in men), liver and breast (in women). Limiting alcohol may also lower the chance of the cancer coming back. To lower the chance of getting cancer, you should limit alcohol, or avoid it altogether. If however you chose to drink, alcohol should be limited to no more than two standard drinks a day to lower the chance over your lifetime from alcohol-related disease or injury.

Complementary therapies

Many people use complementary therapies (sometimes called natural therapies or Eastern medicine) to help them feel better after cancer treatment.

Which therapies work?

There are some therapies that have been proven to be safe and effective in scientific (clinical) studies. The therapies below have been shown to help with the various effects of cancer and its treatment:

Complementary therapy – the evidence

Meditation, relaxation	help reduce stress, anxiety and depression, improve self-esteem and quality of life
Counselling, support groups	help reduce stress, anxiety, depression and pain, and improve quality of life
Art and music therapy	improve quality of life, aid relaxation and expression of feelings
Spiritual practices	help reduce stress, instil peace and improve ability to manage challenges
Massage	may help reduce pain, anxiety, depression, nausea and muscle tension
Aromatherapy	aids relaxation and reduces anxiety
Acupuncture	reduces nausea, vomiting, and improves quality of life
Yoga and physical activity	improve quality of life, sleep, reduce stress, anxiety, depression, fatigue
Tai chi	relieves pain, improves flexibility and strength, and reduces stress
Nutrition	helps wounds and damaged tissue to heal better, improves the body's immune system

[THIS PARAGRAPH IN MANDARIN AND CANTONESE VERSIONS ONLY] Many Chinese people ask about where they can find an acupuncturist. While we do not recommend any particular practitioner, you can search for acupuncturists in your area at the The Australian Acupuncture and Chinese Medicine Association. Visit their website at www.acupuncture.org.au (Chinese translation only).

Let your doctor know about any complementary therapies you are using or thinking about trying. Some therapies may not be suitable depending on your situation. For example, your doctor may advise against a strong, deep tissue massage if you had surgery or bone problems during treatment. Always let the complementary therapist know that you have had cancer.



Seeking support

Remember, you are not alone on this road to recovery. If you have any concerns about your health and wellbeing after having treatment for cancer, speak with your local doctor, specialist or the Cancer Council. There are many services that can help you if you need them.

“ I feel that I am hopeful and the path is still long. ”

Cancer information and support

If you have questions, or want information about cancer in [Cantonese][Greek][Mandarin] the Cancer Council can help.

Simply follow these steps:

- Call 13 14 50, Monday to Friday 9am – 5pm.
- Say the language you need.
- Wait on the line for an interpreter (may take up to 3 minutes).
- Ask the interpreter to contact the Cancer Council Helpline on 13 11 20.
- Talk to the cancer nurse with the help of your interpreter.

This service is available for the cost of a local call (except from mobiles).

To link to the Cancer Council website in your state or territory, go to www.cancer.org.au >about us>Cancer Council websites.

Support groups

NSW

[MANDARIN][CANTONESE] Can Revive helps Chinese cancer patients and their families with information service and support groups. Phone (02) 9212 7789, email info@canrevive.com or visit the website at www.canrevive.com

VIC

[MANDARIN][CANTONESE] Chinese Cancer Society of Victoria supports people from a Chinese backgrounds whose lives are affected by cancer, from diagnosis through to recovery or bereavement. Phone (03) 9898 9575, email enquiry@ccsv.org.au or visit the website at www.ccsv.org.au

[GREEK] The Greek Cancer support group runs monthly meetings in Brunswick. For details, ring the Cancer Council on 13 11 20. For information in Greek through an interpreter, phone 13 14 50.

If there is not a group in your state or territory, these support groups may be able to help you with local information or support in your language.



Useful Websites

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

Cancer Council Australia www.cancer.org.au
Cancer Australia..... www.canceraustralia.gov.au
Australian Cancer Survivorship Centrewww.petermac.org/cancersurvivorship

The websites below have information available in your language. The Victorian site also provides access to the multilingual appointment card and free health sessions.

Cancer Council NSW
..... www.cancercouncil.com.au/publications/multilingual-cancer-information
Cancer Council Victoria www.cancervic.org.au/languages
Cancer Council Australia <http://cald.cancer.org.au/Home.htm>

How this booklet was developed

This resource has been produced as a collaboration with [Chinese] [Greek] community groups and the following key organisations.

Cancer Australia's Supporting people with cancer grant initiative is funded by the Australian Government. The grant initiative allows community organisations to continue to improve coordination, accessibility and development of quality cancer support networks to better support people affected by cancer.

The Australian Cancer Survivorship Centre, A Richard Pratt Legacy is based at Peter MacCallum Cancer Centre. The ACSC has been established to improve health outcomes for cancer survivors. The ACSC's priorities include to improve survivors' access to information and resources.

The Psycho-oncology co-operative research group (PoGoG) aims to improve outcomes for people affected by cancer by developing and facilitating high quality, collaborative and clinically relevant research that focuses on interventions and services to optimise psychosocial and supportive care.

This book is a joint collaboration with:



Australian Government
Cancer Australia

Australian Cancer Survivorship Centre
A Richard Pratt Legacy




Peter Mac 