

# Understanding Rare and Less Common Cancers

*A guide for people with cancer, their families and friends*



For information & support, call **13 11 20**

## **Understanding Rare and Less Common Cancers**

A guide for people with cancer, their families and friends

First published March 2021.

© Cancer Council Australia 2021. ISBN 978-0-9807421-5-2 : ebook - epub

Editor: Rosemary McDonald. Designer: Emma Johnson.

### **Acknowledgements**

This edition has been developed by Cancer Council Australia on behalf of the state and territory Cancer Councils as part of an Australian Government initiative. We thank the reviewers of this booklet: Dr Dani Bullen, Clinical Psychologist, Peter MacCallum Cancer Centre, VIC; Sally Carveth, Cancer Support Consultant, Cancer Council NSW; Tracey Gardner, Senior Psychologist, Cancer Council Queensland, QLD; Dr Anna Hughes, Liaison Psychiatrist and Senior Staff Specialist, Canberra Health Services, ACT Health, ACT; Caitriona Nienaber, 13 11 20 Consultant, Cancer Council WA; Wayne Reynolds, Consumer; Dr Charlotte Tottman, Clinical Psychologist, Allied Consultant Psychologists and Flinders University, SA; Ann Marie Weber, Consumer; Shirley Witko, Senior Social Worker, Sir Charles Gairdner Hospital, WA.

A web-based resource for Australians with less common cancers project is a Cancer Australia Supporting people with cancer Grant Initiative, funded by the Australian Government. Website: [canceraustralia.gov.au](http://canceraustralia.gov.au)

### **Cancer Council**

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

### **Note to reader**

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

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



### **Cancer Council Australia**

Level 14, 477 Pitt Street, Sydney NSW 2000

**Telephone** 02 8063 4100 **Facsimile** 02 8063 4101 **Email** [info@cancer.org.au](mailto:info@cancer.org.au) **Website** [cancer.org.au](http://cancer.org.au)

ABN 91 130 793 725

# About this booklet

This booklet has been prepared to help you understand more about rare and less common cancers.

A cancer diagnosis is a life-changing event, but when you have been diagnosed with a rare or less common cancer, it can be especially challenging. Rare and less common cancers affect only a small number of people. They are more difficult to diagnose than more common cancers, and as a result, are more likely to be diagnosed at a later stage, potentially making them more difficult to treat.

It can be hard to cope with cancer and its treatment, especially if you have been diagnosed with a rare cancer. We hope this booklet will help you understand more about these cancers. It offers suggestions for coping with your diagnosis; making treatment decisions; looking after yourself before, during and after treatment; as well as providing information about support services. As a cancer diagnosis affects not only you but also your family and friends, it also provides practical tips on how to talk to others about cancer. You don't need to read it from cover to cover – just read the parts that are useful to you.

**How this booklet was developed** – This information was developed with help from a range of health professionals and people affected by a rare or less common cancer.



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



# Contents

<b>What is cancer?</b>	<b>4</b>
<b>What is a rare or less common cancer?</b>	<b>6</b>
<b>Key questions</b>	<b>8</b>
What makes a cancer rare?	8
How common are rare cancers?	9
Why is it hard to diagnose rarer cancers?	9
Which health professionals will I see?	10
What tests might I need to have?	12
What type of treatment might I have?	14
Where will I go for treatment?	14
How are treatments improving for rarer cancers?	15
<b>Challenges of coping with a rarer cancer</b>	<b>16</b>
How to tell family and friends	18
When you don't want to talk	20
Ways to share how you are feeling	21
Talking with your partner about your diagnosis	22
Your coping toolbox	23
<b>Making treatment decisions</b>	<b>27</b>
Talking with doctors	27
Should I join a clinical trial?	31
Cancer and your work	32
Cancer and your finances	34

## **Looking after yourself during treatment 37**

Eating well	37
Staying active	38
Doing things that bring you joy	38
Getting plenty of sleep	39
Complementary therapies	40
Relationships	42

## **Life after treatment 43**

Follow-up appointments	44
What if my cancer returns?	46
Living with advanced cancer	47
Palliative care	48
Planning ahead	49

## **Seeking support 51**

Support from Cancer Council	52
Useful websites	53

## **Caring for someone with a rarer cancer 54**

## **Question checklist 55**

## **Glossary 56**

## **How you can help 58**

## **Key to icons**

Icons are used throughout this booklet to indicate:



More information



Alert



Personal story



Tips

---

# What is cancer?

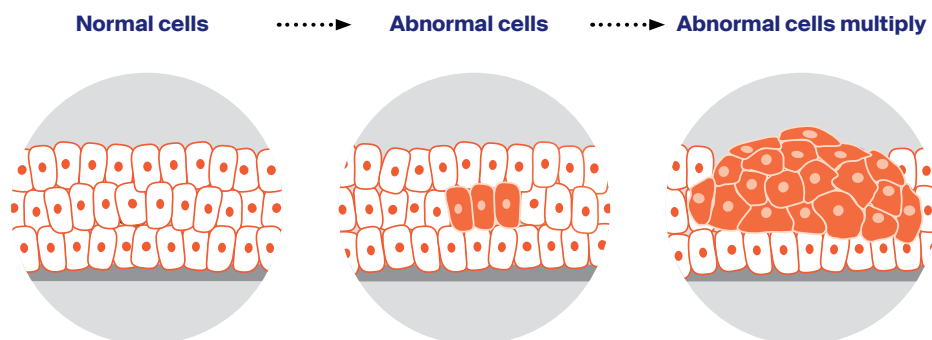
Cancer is a disease of the cells. Cells are the body's basic building blocks – they make up all tissues and organs. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries.

Normally, cells multiply and die in an orderly way, so that each new cell replaces one lost. Sometimes, however, cells become abnormal and keep growing. These abnormal cells may turn into cancer.

In solid cancers, such as bowel or breast cancer, the abnormal cells form a mass or lump called a tumour. In some cancers, such as leukaemia, the abnormal cells build up in the blood.

## How cancer starts

---

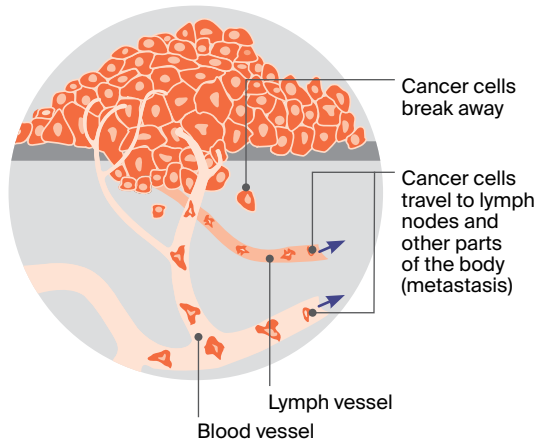
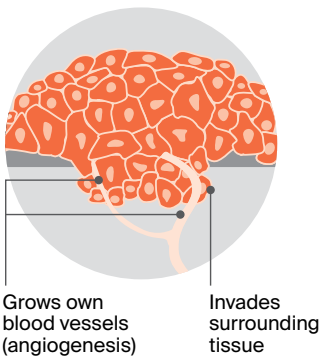


Not all tumours are cancer. Benign tumours tend to grow slowly and usually don't move into other parts of the body or turn into cancer. Cancerous tumours, also known as malignant tumours, have the potential to spread. They may invade nearby tissue, destroying normal cells. The cancer cells can break away and travel through the bloodstream or lymph vessels to other parts of the body.

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

## How cancer spreads

### .....▶ Malignant cancer





# What is a rare or less common cancer?

There are more than 200 different types of cancers that can develop from different types of cells in different parts of the body. Some of these cancers are common, such as breast, bowel, prostate and lung cancer. Other types of cancers are rare, such as small bowel, gall bladder and penile cancer. Prostate cancer, for example, is one of the most common cancers with about 19,000 cases (140 cases per 100,000 people) being diagnosed each year in Australia. Penile cancer, on the other hand, is a rare cancer, with only about 103 cases (0.8 cases per 100,000 people) being diagnosed in Australia each year.<sup>1</sup>

Each rare and less common (RLC) cancer affects only a small number of people. In Australia, a rare cancer is defined as one which has fewer than 6 diagnoses per 100,000 people and a less common cancer is one which has fewer than 12 diagnoses per 100,000 people. Each year, about 145,000 Australians are diagnosed with cancer and of these, about 52,000 will have their cancer diagnosed as rare or less common.<sup>2</sup>

This means that while there will only be a small number of each type of RLC cancer diagnosed each year, one in three people diagnosed with cancer in Australia will have a RLC cancer. Also, RLC cancers account for half of all cancer deaths in Australia and seven per cent of all diseases.<sup>3</sup>

Over the last 20 years, while the incidence rate for common cancers has increased, death rates have decreased significantly. This is a result of better screening, early detection and advancements in treatment.

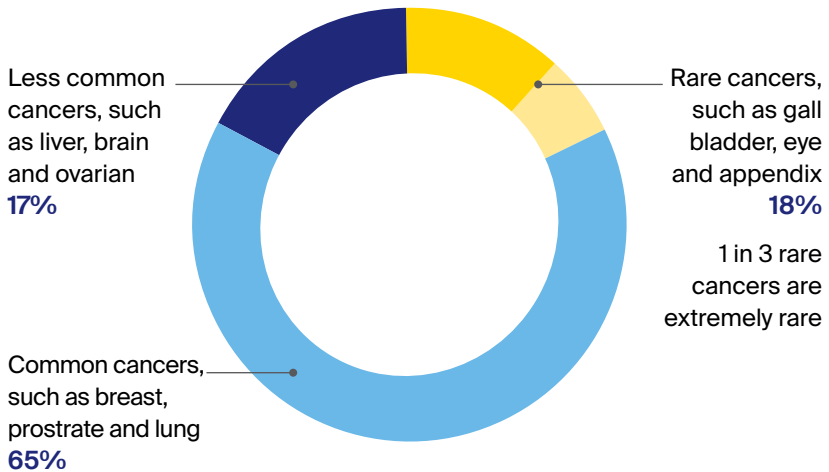


People diagnosed with a rare or less common cancer, however, face a greater challenge. These cancers are often more difficult to diagnose than common cancers, and as a result, are more likely to be diagnosed at a later stage. Also, as numbers for RLC cancers are small, research often does not progress quickly. In recent years, treatments for many rare cancers have not advanced at the same pace as treatment for more common cancers.

## Percentage of common, less common and rare cancers in Australia<sup>4</sup>

---

Each year, about 145,000 Australians are diagnosed with cancer and of these, about 52,000 will have their cancer diagnosed as rare or less common. So around one in three people diagnosed with cancer are diagnosed with a rare or less common cancer.





# Key questions

## Q: What makes a cancer rare?

**A:** A cancer is considered rare or less common when it affects only a small number of people. There are many different types of RLC cancers. They can start in many different parts of the body and from different types of cells. Some may originate in a part of the body, such as the bowel, where other more common cancers arise, but from a different type of cell to the more common cancer, making it rare.

A cancer might be rare because it is found in an unusual part of the body for that type of cancer. For example, melanoma is a type of skin cancer commonly diagnosed in Australia, but melanoma that starts in the eye is very rare.

A cancer might be rare as it is a subtype of a more common cancer. For example, lymphoma is a common cancer in Australia but there are some subtypes that are rare such as some T-cell lymphomas.

Cancers are considered rare if they affect a child or a teenager. Cancer only affects a very small number of children and teenagers so any cancer that is found in a child is considered to be rare.

A cancer might be common in one sex but rare in the other. For example, about 19,000 women are diagnosed with breast cancer in Australia each year but only around 130 men. This makes breast cancer in men rare.<sup>4</sup>

## **Q: How common are rare cancers?**

**A:** A cancer is considered rare if it affects fewer than 6 people per 100,000 each year and less common if it affects fewer than 12 people per 100,000 each year. In Australia, around 145,000 people are diagnosed with cancer each year. RLC cancers account for around 52,000 of these cancers, which is about one-third of all cancer diagnoses. But RLC cancers account for 50 per cent of cancer deaths.

## **Q: Why is it hard to diagnose rarer cancers?**

**A:** RLC cancers are often difficult to diagnose for a number of reasons:

- Your symptoms may be like those caused by more common conditions. For example, shoulder pain may be a muscular condition or a symptom of cancer. Often the doctor will explore the more common reason first leading to a delay of a diagnosis.
- Symptoms of some RLC cancers are unusual and as a result are less well known to doctors than symptoms of more common cancers.
- Sometimes cancer develops in a person who is not expected to get cancer. This is the case with children and adolescents. Doctors will often look for other causes for their symptoms first.
- You may need to have several tests and see more than one specialist before you get a diagnosis. Often doctors and pathologists don't have enough information on rarer cancers and people may receive an incorrect diagnosis first before receiving the correct diagnosis.
- The pathologist may need to do a number of tests on your biopsy or blood sample, or may have to send the sample to a specialist laboratory for testing. This can all result in a delay to the diagnosis.

## Q: Which health professionals will I see?

**A:** Usually, your general practitioner (GP) will arrange the first tests to assess your symptoms. If these tests do not rule out cancer, you will usually be referred to a specialist who will arrange further tests. To find out and understand what type of cancer you have, you may be referred to more than one specialist.

### Health professionals you may see

<b>GP</b>	assists with treatment decisions and works in partnership with your specialists in providing ongoing care
<b>surgeon*</b>	surgically removes tumours and performs some biopsies; specialist cancer surgeons are called surgical oncologists
<b>medical oncologist*</b>	treats cancer with drug therapies (systemic treatment) such as chemotherapy, targeted therapy and immunotherapy
<b>radiation oncologist*</b>	treats cancer by prescribing and overseeing a course of radiation therapy
<b>pathologist*</b>	examines cells and tissue samples to determine the type and extent of the cancer
<b>cancer care coordinator</b>	coordinates your care, liaises with other members of the MDT and supports you and your family throughout treatment; care may also be coordinated by a clinical nurse consultant (CNC) or clinical nurse specialist (CNS)

The health professionals you will see will depend on the type of cancer you have. Your specialist may discuss your treatment options with other health professionals at what is known as a multidisciplinary team (MDT) meeting. During and after treatment, you may see a range of health professionals who specialise in different aspects of your care.

<b>nurse</b>	administers drugs and provides care, information and support throughout treatment
<b>dietitian</b>	recommends an eating plan to follow while you are having treatment and in recovery
<b>social worker</b>	links you to support services and helps you with emotional, practical and financial issues
<b>physiotherapist, occupational therapist</b>	assist with physical and practical problems, including restoring movement and mobility after treatment and recommending aids and equipment
<b>psychiatrist*, psycho-oncologist*, psychologist, counsellor</b>	help you manage your emotional response to diagnosis and treatment
<b>palliative care specialist* and nurse</b>	work closely with the GP and cancer specialists to help control symptoms and maintain quality of life

*\* Specialist doctor*

## Q: What tests might I need to have?

**A:** Rare and less common cancers can be difficult to diagnose. To find out what type of cancer you have, you may have a number of tests to look for the cause of your symptoms. You will often have to have more tests than people with more common cancers.

The first test you may have is a physical examination to check for lumps, enlarged organs, or to look for other signs of cancer. If your doctor thinks you might have cancer, they will arrange for you to have further tests.

To diagnose most cancers, doctors will need to remove a sample of tissue from the affected area and have the cells examined under a microscope by a pathologist. This is called a biopsy. The type of biopsy you have will depend on the symptoms you are experiencing, the area of concern for the doctor and where the area is located in your body.

For blood cancers such as leukaemia and lymphoma, and some other cancers, you will have blood tests to measure your white blood cells, red blood cells and platelets, as well as to measure tumour markers (chemicals produced by cancer cells) and to check if you have an infection. You may also have a urine test to check for blood and bacteria.

If tests show that you may have cancer, you will have some further tests. These are to find out about the cancer and whether it has spread. Often called staging scans, these tests might include an ultrasound and scans such as a CT (computerised tomography) scan, a PET (positron emission tomography) scan or an MRI (magnetic resonance imaging) scan. Tests could also include

an endoscopic examination which allows doctors to see inside your body using a small camera.

Doctors will use the information from these tests to work out the type of cancer you have and the best treatment for you.

## Waiting for test results

---

Waiting for test results can be an anxious time. It may take from a few days to a couple of weeks for the results of your tests to be ready. Many people feel anxious during this time. You may feel that your future is very uncertain and that you have no control over what is happening to you.

There is no right or wrong way to deal with these feelings. Some people try to continue on with normal activities, such as going to

work, as this is a good distraction from worrying about the test results. Other people, however, may feel they can't concentrate on anything else.

While you are waiting, it might help to talk to a close friend or relative about how you feel. To find a good source of support, call Cancer Council 13 11 20 where trained professionals will answer any questions you may have, or provide you with helpful resources.

---

*“I knew that worrying about my test results wouldn't change the diagnosis so I tried to focus on things that made me feel calm and relaxed.”* SARAH

## **Q: What type of treatment might I have?**

**A:** Depending on the type of cancer you have and how advanced it is, your treatment options may include conventional methods such as surgery, radiation therapy and chemotherapy, or newer treatments such as immunotherapy and targeted therapies. You may also be offered treatments through clinical trials.

Some people with cancer will have only one treatment, but many people need a combination of treatments, such as surgery with chemotherapy and/or radiation therapy. Sometimes treatments can be given at the same time. An example of this is chemoradiation, which is when radiotherapy and chemotherapy are given at the same time. Your specialist will work with a multidisciplinary team to recommend the best treatment options for you.

## **Q: Where will I go for treatment?**

**A:** Where you go for treatment will depend on where you live. Capital cities and larger regional centres have specialised centres that treat cancer. But if you have a rare cancer, you may find that not all the services you need will be offered by your local centre and you may have to travel to another hospital. Your doctor will advise you.

Rare Cancers Australia have a directory of health professionals and a list of Australian hospitals, treatment centres and hospices with cancer care services with both public and private service centres listed. Call 1800 257 600 or visit [rarecancers.org.au](http://rarecancers.org.au). Depending on the type of rare cancer you have, there may also be a support organisation that you can contact for a directory of specialists and treatment centres. The Cancer Council also has a list of public and private treatment centres. Call 13 11 20 for more information.



## Q: How are treatments improving for rarer cancers?

**A:** Many significant advances in cancer treatment have occurred over the last 30 to 40 years, including in early detection, surgery, radiation therapy, chemotherapy and immunotherapy. But often treatments for rarer cancers don't develop as quickly. There are a number of reasons for this.

- Due to lower incidence rates, research into rare cancers attracts less funding than research into more common cancers.
- Researchers have less access to tissue samples of rare cancers restricting their ability to discover how the cancers develop and respond to treatment.
- Clinical trials of new treatments for rare and less common cancers are more difficult to conduct due to the low number of patients. Clinical trials usually rely on large groups of people who have a similar condition.
- The systems for approving a medication or a new way to treat a particular cancer can take years or decades and are often not flexible enough to enable approval of new treatments for a small group of patients.

Despite these challenges, targeted future therapies for rare and less common cancers are being developed. Research into genome sequencing and genetic testing offer a chance of earlier intervention, individualised therapies and also holds potential to improve the quality of life for people with rare and less common cancers.



# Challenges of coping with a rarer cancer

Coping with any cancer diagnosis is challenging, but if you have been diagnosed with a rare or less common cancer, you may experience added distress and feel a range of strong emotions, such as shock, disbelief, fear, sadness, isolation and anxiety.

You may worry about what it means for your way of life now and in the future. You may be concerned about how to tell family and friends, how to make sure children are looked after, whether you can keep working, and how you will manage financially. You might feel angry if it has taken longer to get a diagnosis. You may not know anyone else with this type of cancer. And you might be finding it difficult to get information about your type of cancer.

Two issues people with a rare or less common cancer often have to face are increased uncertainty and isolation. Cancer always brings uncertainty. You don't know when you are first diagnosed what treatments you will have, how long the treatments will take, where you will be treated and what the outcome will be. But uncertainty can be even greater with a RLC cancer. Often there is less information available about your cancer and this means it can be harder for doctors to answer your questions or tell you what may happen. Your doctors may not have treated this cancer before, or only treated a small number of patients with it, so it can be challenging for them as well.

Many people with cancer can feel isolated, but if you have a rare or less common cancer, this can be even more of a challenge. You may feel

emotionally and even physically isolated, perhaps needing to travel to a hospital far away from home for treatment, meaning you have to be away from the family and friends who usually support you. You may have to give up work while you have treatment, leaving you feeling even more isolated from work colleagues and from your usual routine.

Your cancer may be treated in a different way to more common cancers and you may feel that your family and friends do not understand what you are going through. Talking to people who have the same type of cancer can be helpful and can make you feel less alone. But if you have a rare or less common cancer, connecting with people with the same type of cancer can be difficult.

It is natural to feel overwhelmed by your cancer diagnosis. Finding reliable information and the right kinds of support can help. Your cancer team can be an important source of support for you. It is important that you talk to them and tell them how you are feeling and if there are things you are finding hard to cope with. They can refer you to a counsellor, psychologist, psychiatrist or another health professional trained to help people manage how they are feeling. They may also be able to put you in touch with other people who are going through similar treatment.

Cancer Council offers a range of support services for counselling, peer support, support groups, legal and financial assistance, practical support and information in other languages. Call 13 11 20.

► See *When you are first diagnosed* on our website to find information you may need after diagnosis. See also Cancer Council Queensland's *Coping with Cancer* booklet.

## How to tell family and friends

You will have to work out who you are going to tell that you have cancer and what you are going to say. When you feel ready, start preparing for these conversations by:

- thinking of answers to likely questions (but remember you don't have to share every detail)
- accepting that the person you are telling may get upset and you may, in some cases, find yourself comforting them
- getting help finding the right words, for example you could meet with the hospital social worker or call Cancer Council 13 11 20 to talk through what you might say.

The reactions from your family and friends will depend on many factors, including their previous experience of cancer and their own coping styles. Some people become very distressed and will have a strong reaction to the word “cancer”, especially when you tell them it is a rarer cancer. Some people will say the wrong thing or won't know what to say. Others might feel that they can't cope with what you are going through and seem to avoid you. Try not to take their initial reactions as a sign they don't care. They might be fearful of losing you, frustrated they can't do anything about the disease, or be worrying about how the illness will change their lives. Give your family and friends time to adjust to the diagnosis. After the initial shock, most people will be supportive.

*“People usually don't mean to make things worse. Their reactions are likely to come from their own difficulties in handling feelings such as fear and anxiety, or from uncertainty about what to do or say.”* DANI

## How to tell children

---

Talking to your children about your cancer diagnosis can feel overwhelming. Your first reaction may be to keep the news from them or to delay telling them. Even though it can be difficult, research shows that being open and honest helps children cope with the cancer diagnosis of someone close to them.

Talk to your children as soon as you feel able to. Keeping the diagnosis a secret can be stressful for you and your children will probably sense something is wrong. Depending on their age, break the news with a few short sentences explaining what you know so far and what will happen next.

Be clear about the name of the cancer, the part of the body that has the cancer and how it will be treated. Start with small amounts of information and ask them what they want to know. Don't assume children will have the same concerns as you.

Let your children know that they can ask you any questions at any time about your cancer, and if you don't know the answer then and there, you will find out and get back to them.

Your children are likely to want to know what treatment will mean for them. If you are in hospital, who will drop them off at school, make them dinner, take them to after-school activities? Reassure them that there will be a plan and you will let them know what it is.

Balance hope with reality. Tell your children that although cancer can be serious and going through treatment can be hard, many people get better. Explain that with the help of the doctors, you (or the person with cancer) will be doing everything possible to get better.

Show your love and emotions. Tell your children that you love them and show your love by hugging them and making them feel safe. Some parents worry about crying in front of their children, but this is okay. It can be helpful for them to know that strong feelings such as anger and sadness are normal and expressing them can make people feel better.

► See our *Talking to Kids About Cancer* booklet.

## When you don't want to talk

It can be difficult to tell people you have cancer. You may find that you don't want to talk about the cancer and its treatment or about your fears and concerns with your family and friends. This may be because you feel uncomfortable discussing private matters, you don't have the words to describe how you feel, or you fear becoming upset.

You may feel you don't want to burden your family and friends and don't want to alarm the people you love. You may feel that you don't want cancer to define you or you don't want people to pity you. You may also feel that doing normal, day-to-day things and not talking about your cancer diagnosis is the best way for you to cope. Sometimes putting things into words makes it seem more real.

Everyone handles a cancer diagnosis in their own way, and that has to be respected, but not talking about your cancer can cause problems after a while. It may become hard to make decisions about what treatment to have or about if you will continue working during your treatment. This could delay the start of treatment and cause problems with your finances or your relationships.

If you do not feel ready to talk, you could say, for example, "Thank you for asking how I am. I'll let you know when I feel ready to talk."



In some cultures, cancer may be seen as contagious, sent to test you, caused by bad luck and always fatal. People may not want to talk about it openly and may not want to use the word "cancer". If it is hard to talk about cancer within your community, you could call Cancer Council 13 11 20 for another source of confidential support.

## Ways to share how you are feeling

Sometimes it is hard to share how you are feeling and you may find yourself switching between wanting to talk about what's going on and wanting to avoid difficult thoughts and feelings. It is okay to say no – whether it is about discussing your personal concerns or in response to an offer of help.

Repeating the same information to everyone in your network can be draining, and you may not always feel up to taking phone calls or seeing visitors. It can be helpful for one family member or friend to act as the main point of contact. They can answer enquiries, monitor calls, or keep visits to more suitable times. You could also leave a message on your voicemail or answering machine giving a quick update; send text messages or emails; or share updates through social media, such as a closed Facebook group.

If you are having trouble talking to others about personal issues, try joining a support group. Talking about your fears and concerns with people who are going through a similar experience can often be easier. Talk to your health professional who can recommend a group for you or call Cancer Council 13 11 20. It may also be that an appropriate group has not been established due to the rarity of the cancer, so there can be the opportunity to start one of your own.

If you are having trouble expressing how you are feeling, you could try keeping a journal or blog, or you may prefer to play music, draw, paint or make craft. You can choose whether to share your writing or artworks with those close to you or to keep them for yourself.

► See our *Emotions and Cancer* booklet.

## Talking with your partner about your diagnosis

Cancer changes the lives of both people in a relationship and talking about cancer with your partner may be challenging because it often involves intense emotions. These emotions can be heightened when you have had a diagnosis of a rare or less common cancer. Even couples who communicate well may have trouble talking about cancer as it includes topics that are hard to talk about such as sexual issues, fertility issues, physical issues, financial problems and possibly even death and dying.

The effects of a cancer diagnosis can vary from couple to couple. For some couples, facing the challenges of cancer and its treatment together can strengthen their relationship. For others, the stress of living with cancer and its treatment can create new problems or worsen existing problems.

Cancer often changes a couple's hopes and dreams. You might have planned for parenthood, to move to a new house, a promotion at work, an early retirement, or to go travelling together. Now you may need to re-evaluate priorities and work together to establish new short-term goals, such as finishing cancer treatment. Things that seemed important before the cancer diagnosis may change to other priorities. But you might want to consider putting some goals on hold, rather than scrapping them, as this may help you get through treatment and look forward to the future.

If you are having trouble talking with your partner you might consider meeting with a counsellor or psychologist. They can help guide you through the difficult topics. Talk to your GP, hospital social worker or call Cancer Council 13 11 20 to ask about a referral.

- ▶ See Cancer Council Queensland's *Partners guide to coping with cancer* booklet.



## Your coping toolbox

Most of us have various ways of coping with difficult situations, which we have learned over time. These could include:

- seeking more information
- trying to fix the problem
- denying the problem
- having a laugh to feel better
- trying to be strong and “soldiering on”
- distracting ourselves from unhelpful thoughts and feelings
- trying to put things into perspective
- asking for help
- talking things through to try to make sense of what is happening.

It is important to think about what has worked for you in the past but accept that after a cancer diagnosis you might need more than your usual ways of coping. There is no best or right way of coping but having a few strategies may help you feel more in control.

Some coping strategies are less helpful, however. Many people go back and forth between denial and acceptance as they come to terms with a cancer diagnosis. When denial is ongoing, it can become hard to make decisions about treatment, or it could mean you avoid treatment or follow-up appointments. Some people use alcohol and drugs to cope with stressful situations. These may appear to provide relief in the short term but can cause emotional and physical harm and could affect how well the cancer treatment works.

If you think you might be in denial or starting to rely on alcohol or drugs to cope, it is important to talk to your cancer care team about getting professional support. With the right help, it is possible to learn new ways of coping.

## Tools for coping

A coping toolbox is a set of strategies or “tools” you can use to help you cope with a cancer diagnosis and treatment. Each person’s toolbox will look different, but it’s

### Find out what to expect



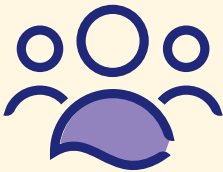
Information about the diagnosis and treatments can help you make decisions and plan ahead, and may make you feel more secure.

### Be active



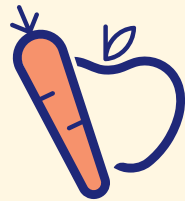
Research has shown that regular physical activity can help with feelings of anger, stress, anxiety and depression. It can also help manage fatigue and improve sleep. Even a short daily walk offers benefits. See our *Exercise for People Living with Cancer* booklet.

### Seek support



Share your concerns with a family member or friend, or with your GP, nurse, social worker or psychologist. Try calling Cancer Council 13 11 20, or visit the Online Community at [cancercouncil.com.au/OC](http://cancercouncil.com.au/OC). Accepting help with practical tasks such as shopping may also help. See pages 51–53 for more sources of support.

### Eat and drink well



Eating healthy food and drinking plenty of water will help your body cope with physical and emotional stress, but this can be challenging when you are feeling unwell. Talk to a dietitian and see our *Nutrition and Cancer* booklet for tips.

useful to consider a range of strategies. Some of these are ways to solve particular problems; others aim to enhance your general wellbeing during this stressful time

## Take a break



Make time each day just for relaxation and enjoyment. Think about things that help you to relax and feel good, such as listening to music, reading, taking a bath or having a massage. Keeping in touch with the world through work, hobbies, or time with family and friends may help you see a life outside of cancer and provide a break from your worries.

## Sort out issues



A cancer diagnosis can cause financial problems, work-related issues, relationship concerns and family stresses. There is support available – talk to the hospital social worker or call Cancer Council 13 11 20.

## Clear your mind



Complementary therapies, such as relaxation, mindfulness meditation, yoga and counselling, may increase your sense of control, decrease stress and anxiety, and improve mood. See pages 40–41 for more information.

## Draw on spirituality



Some people find comfort in their faith and spiritual beliefs. It may help to talk about your feelings with a spiritual care practitioner or religious leader.



## Nicole's story

*I was diagnosed with stage 3 soft tissue sarcoma when I was 27 years of age. Not only had I never heard of 'undifferentiated pleomorphic sarcoma' I couldn't even pronounce it! This type of cancer is rare – only 1500 Australians are diagnosed with a soft tissue sarcoma each year.*

*Most sarcomas don't cause symptoms until they have spread, but my diagnosis came as a result of a 'misdiagnosis'. My doctor thought I was having trouble with my gall bladder, so I had a scan which showed a large tumour near my pancreas.*

*Being diagnosed with a rare cancer can make you feel totally isolated. Both my radiologist and surgeon had never treated my cancer before – they had only read about it in textbooks! It's terrifying when your doctors aren't familiar with the disease you have!*

*When I began my treatment, I started meeting people who knew about sarcomas and also meeting*

*people who had also been diagnosed with a rare or less common cancer. I soon began to realise that although my cancer was rare, I wasn't alone.*

*I was meant to have six rounds of chemo, but I developed some side effects so had to stop after my fourth round. I then had surgery to remove the tumour and within six months of my diagnosis I was cancer-free.*

*I still have regular check-ups to confirm that the cancer hasn't come back but I am optimistic and hopeful about what life holds for me.*

*The overall experience had lots of ups and downs but finding a support group really helped. It's good to be with other people who have been through the same experience and can talk about it. It makes you feel less isolated as these people understand what you are going through.*



# Making treatment decisions

Making treatment decisions when you have been diagnosed with a rare or less common cancer can be overwhelming. Your cancer may have been more difficult to diagnose and as a result, it was diagnosed at a later stage. You may feel that the treatment options for a rare or less common cancer are more limited and less effective than for a more common cancer. You may want very detailed information about your diagnosis and treatment options, or you might prefer to leave treatment decisions to your doctors. You may be anxious to start treatment immediately or you may feel that everything is happening too fast.

► Listen to our *Making Treatment Decisions* podcast

## Talking with doctors

Take your time in talking with your doctors. Understanding the disease, the available treatments, possible side effects and any extra costs can help you weigh up the options and make well-informed decisions. Check with your specialist how soon treatment should begin – sometimes it won't affect the success of the treatment if you wait awhile. Ask them to explain your options and take as much time as you can before making a decision.

## Know your options

Depending on your cancer type you might have a range of treatment options or your options may be more limited. With more common cancers, treatments are based on established guidelines for the best care for that specific type of cancer. For RLC cancers, however, guidelines have not been developed as numbers of these cancers are

low. Treatment for RLC cancers can be quite different from treatment approaches for more common cancers. Even where the rare cancer is a subtype of a more common cancer, the approach may need to be quite different.

In general, your treatment options will depend on:

- the type of cancer you have
- the stage and grade of the cancer
- other tests that might be needed to give more information about your cancer, for example genetic tests
- your overall health
- any other medical problems you might have
- your personal preferences.

## **Treatment team**

Your treatment will be planned and managed by a team of health professionals called a multidisciplinary team (MDT). Some rare cancers are subtypes of more common cancers and are managed by the MDT for that type of cancer. But in other cases, treatment will be very different, and you may be referred to another MDT with experience of that subtype.

If you have a rare cancer, you may need to travel to a specialist centre to see doctors who have experience in that type of cancer. The treatment may be planned by an MDT at the specialist centre and given in a hospital closer to home. Or the treatment may be highly specialised and given in the specialist centre.

## **Record the details**

When your doctor first tells you that you have cancer, you may not remember everything you are told. You will likely have many medical

appointments. Taking notes can help or you might like to ask if you can record these discussions. It is a good idea to have a family member or friend go with you to appointments to join in the discussion, write notes or simply listen.

## Ask questions

You are likely to have a lot of questions to ask your doctor. If you are confused or want to check anything, it is important to ask questions. Try to prepare a list before each appointment (see page 55 for some suggestions). If you have a lot of questions, you could talk to a cancer care coordinator or nurse.

## Consider a second opinion

You may want to get a second opinion from another specialist to confirm or clarify your specialist's treatment recommendations or reassure yourself that you have explored all of your options. Specialists are used to people doing this. Your GP or specialist can refer you to another specialist and send your initial results to that person. You can get a second opinion even if you have started treatment or still want to be treated by your first doctor. You might decide you would prefer to be treated by the second specialist.

## It's your decision

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

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



## **Ann Marie's story**

---

*I started having issues with my vision and had been suffering migraines for some time when I was referred by my optometrist for a CT scan of my brain. The wait for the results was a very anxious time!*

*The results showed I had a detached retina, so I was referred to a specialist for more tests. When the results came back the words of the specialist will be forever etched in my brain. "You have a tumour in your right eye which is causing your retina to be detached and I believe it is ocular melanoma."*

*Ocular melanoma is a rare cancer. Only about 350 Australians are diagnosed with it each year. Most people have heard of melanoma that develops on the skin but not on the inside of the eye that has never been exposed to the sun!*

*I was referred to a radiation oncologist in Sydney and we discussed the options of enucleation (removing the eye) versus stereotactic*

*radiation. I opted for the radiation! I underwent five doses of intense radiation – it wasn't easy, but it was not as bad as I had anticipated.*

*Recovery was tough – loss of hair, chronic fatigue and worst of all, complete loss of vision in my right eye.*

*The following months I really struggled with my dreadful vision, and while the tumour was showing signs of shrinkage, I made the decision to have my eye removed. Twelve weeks after surgery, I received my prosthesis which was a very exciting time.*

*I am really happy with the result. Ocular melanoma has made me a different person. I used to be driven by work and the desire for financial security. Now I take time to enjoy the little things and live the best life I can. My personal motto is no matter how you feel, get up, dress up, show up and never give up!*



## Should I join a clinical trial?

---

As part of your treatment, your health professionals may suggest you take part in a clinical trial, or you can ask them if there are any clinical trials available for you. Clinical trials are medical research studies in which people volunteer to test new treatments, interventions or tests as a means to prevent, detect, treat or manage various diseases or medical conditions.

Doctors use clinical trials to:

- test new or modified treatments to see if they work better than existing treatments
- find new treatments that have fewer side effects
- find new ways to combine treatments to see if they work better
- test new cancer drugs to find out more about the drugs and their side effects
- improve the ways treatments are given to improve outcomes and reduce side effects.

Results from clinical trials can help improve cancer treatments and help people live longer. If you decide to take part in a clinical trial you will be given information about

the trial and it is important to understand what is involved before agreeing to take part. You can ask the research nurse or doctor any questions you might have.

If you join a randomised trial for a new treatment, you will be chosen at random to receive either the best existing treatment or the modified new treatment. Over the years, trials have improved treatments and led to better outcomes for people diagnosed with rare or less common cancers. You may find it helpful to talk to your specialist, clinical trials nurse or GP, or to get a second opinion. If you decide to take part in a clinical trial, you can withdraw at any time.

For more information, visit [australiancancertrials.gov.au](http://australiancancertrials.gov.au).

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

## Cancer and your work

After a cancer diagnosis, many people worry about how it will affect their ability to work. In most cases, cancer will affect some aspects of your work life as most of your treatment appointments will be scheduled during business hours.

Whether you are able to work during treatment will depend on:

- the type and stage of your cancer
- the type of treatment you have and its side effects
- how you feel during treatment
- the kind of work you do
- if you work full-time, part-time, you are casual or self-employed, and if you work in an office or at home
- your employer.

Discuss the demands of your job with your health care team. Ask them how much time off you are likely to need or whether you will be able to work throughout your treatment and recovery.

Your decision about working will also depend on the support and flexibility of your employer. Most people who want to keep working during treatment are able to do so in some capacity. Some people manage by adjusting their work hours – they may miss a couple of days here and there or work part-time. Others choose to take a break or retire. Each person's situation will be different and it's best to do what feels right for you.

Talking to your employer can give you peace of mind. You can also check with a social worker or Cancer Council whether any financial assistance is available to you.

► See our *Cancer, Work & and You* booklet.



## How to talk to your employer

Telling your employer that you have cancer is a personal decision. While you don't have to share the diagnosis with your employer, you do have some obligations. You must tell them about anything that will affect your ability to do your job.

- You may feel more confident talking to your employer if you practise what you want to say with your family and friends first.
- Decide beforehand how much information you want to share. Prepare some notes so you don't forget anything.
- Consider taking a support person with you to help with the discussion.
- Request a meeting in a quiet, private place where you won't be interrupted. Allow plenty of time for your discussion.
- Come to the meeting with some ideas about your needs and how any impact on the workplace can be dealt with.
- Reassure your employer of your commitment to your job.
- Be prepared for your employer to bring up your working arrangements, e.g. they may ask if you want to change your work schedule. If you don't know, say that you need time to think about your options.
- Keep notes about the discussion. Write down any agreed changes to your working arrangements for you and your employer to sign.
- Don't feel that you have to agree on everything in the first meeting. You may both need to get more information.
- Refer your employer to Cancer Council's online Workplace Fact Sheets for employers and workplaces. Cancer Council Pro Bono Legal & Financial Service can also assist you with work issues. Check your local Cancer Council website, call Cancer Council 13 11 20, or see a social worker in your treating hospital for a referral.

## Cancer and your finances

After a cancer diagnosis, many people worry about how they will manage the financial impact of having cancer.

There are many different types of costs that can add up during diagnosis, treatment and recovery. These will vary depending on your cancer type, stage and treatment options. You may have health-related expenses, such as medicines, equipment and specialist fees. There can also be extra costs for transport, parking, accommodation, childcare or complementary therapies. At the same time, cancer may mean a loss of income if you or your partner/carer has to take time off work. At a time when people should be focused on their treatment and recovery, these costs can be a source of stress and worry.

Before you decide whether to have treatment as a private or public patient, ask your doctor and hospital:

- how much will consultations and treatment cost
- will there be any up-front or out-of-pocket (gap) expenses
- do they offer flexible repayment plans?

The out-of-pocket costs associated with cancer may include:

- general practitioner (GP) and specialist gap payments
- hospital admissions, scans or tests outside the public health system
- Pharmaceutical Benefits Scheme (PBS) and over-the-counter medicines
- medical appliances and devices such as a prosthesis
- travel and accommodation
- personal care, such as managing side effects from your treatments.

If you have private health insurance, ask the insurer about the gap cover. Gap cover insures you against some of the difference between what a

hospital or specialist charges you and what Medicare will give you back (the gap payment). Health funds make arrangements with individual doctors about gap payments. Choosing to see the doctors and hospitals that participate in your health insurer's medical gap scheme can help to reduce any out-of-pocket costs that you may be charged.

People who live further away from the treating hospital may have extra expenses. If you need to travel away from home for treatment, financial help is available for transport and accommodation costs (see following page).

The Australian Government offers several benefits that can help you access medical treatments, tests, prescription medicines and other medical supplies at a lower cost. These are:

**Medicare Safety Net** – this provides financial relief for people with high medical costs by reducing their out-of-pocket costs. Once a threshold is met, Medicare will pay a higher benefit for many services until the end of the calendar year. You will usually receive notification from Medicare that you have reached the Safety Net.

**PBS Safety Net** – the PBS subsidises the cost of most prescription medicines for all Australian residents with a current Medicare card. The PBS Safety Net further reduces the cost of prescription medicines once you or your family have spent a certain amount on prescription medicines. It resets at the beginning of each year.

**Medicare benefits for allied health services** – if you have a chronic health condition (one present for at least six months or that is terminal), you may be able to get Medicare benefits for allied health practitioners, such as physiotherapists, podiatrists, dietitians and

psychologists, to help manage your condition. Under a Chronic Disease Management Plan, your doctor can refer you to at least two allied health practitioners for your condition, and you can claim at least part of their fees on Medicare.

**Medicare benefits for mental health services** – you may be able to get Medicare benefits for mental health practitioners such as clinical psychologists and general psychologists. Under a Mental Health Care Plan, your GP can refer you to a mental health practitioner, and you can claim at least part of their fees on Medicare.

**Transport costs** – each state and territory has a government scheme that provides financial help to people who need to travel long distances to access specialist medical treatment that is not available in their local area. Many schemes include accommodation. In some cases, financial assistance may also be available if you need an escort or carer to travel with you to your treatment. Talk to your doctor or call Cancer Council 13 11 20 to see if you are eligible.

If you are struggling financially, talk to your doctor as they may suggest ways to reduce your treatment costs or they might be able to keep seeing you as a public patient. Seeking financial advice can give you peace of mind. There are several specialist financial and support services available. Talk to your social worker or call 13 11 20 to find out more.

► See our *Cancer and Your Finances* booklet.

# Looking after yourself during treatment

Cancer and cancer treatment can cause physical and emotional strain, so it's important to look after yourself. Cancer Council has free booklets and programs to help you during and after treatment. Call 13 11 20 to find out more or visit your local Cancer Council website (see back cover).

## Eating well

If you have been diagnosed with cancer, both the disease and treatment will place extra demands on your body. Research shows that eating well benefits people before, during and after cancer treatment. It can:

- improve quality of life by giving you more energy, keeping your muscles strong, helping you stay a healthy weight, and boosting mood
- help manage the side effects of treatment, improve response to treatment, reduce hospital stays, and speed up recovery
- help heal wounds and rebuild damaged tissues after surgery, radiation therapy, chemotherapy or other treatment
- improve your body's immune system and ability to fight infections
- reduce the risk of cancer coming back.

During your treatment you may need to eat more kilojoules/calories. Eat small, frequent meals or snacks rather than three large meals. If you start to lose weight you will need practical suggestions on how to gain weight. Doing some light physical activity, such as walking, can improve your appetite, help digestion and prevent constipation. Your GP, cancer specialists and cancer nurses can help answer your questions about nutrition or you can talk to a dietitian at your treating hospital.

► See our *Nutrition and Cancer* booklet.

## Staying active

Along with eating well, physical activity is important for general health and wellbeing. Exercise can reduce tiredness, improve circulation, increase appetite and lift mood.

Exercise is now recommended for most people during and after cancer treatment. Research shows that regular physical activity can:

- improve the effectiveness of some cancer treatments
- help manage fatigue and other common side effects of cancer treatment
- increase appetite
- speed up recovery
- strengthen muscles and bones
- improve circulation and energy levels
- reduce stress and improve your mood
- reduce the risk of the cancer coming back (for some cancer types) and of developing other health problems
- improve quality of life.

The right exercise for you depends on what you are used to, how you feel, and your doctor's advice. Check with your doctor before starting an exercise program and see a physiotherapist or exercise physiologist to develop an exercise plan that suits your situation. A physiotherapist or exercise physiologist may be part of the team at your hospital or treatment centre, or your GP can refer you to one in private practice.

► See our *Exercise for People Living with Cancer* booklet.

## Doing things that bring you joy

There is no one-size-fits-all activity that brings us joy, pleasure, relaxation and happiness – for some it might be gardening, while for others it might be listening to music. Think about what you love and



continue to do those things or try introducing new activities into your routine. These could include:

- being in nature
- practising yoga
- rereading a favourite book
- listening to podcasts or audio books
- listening to music
- painting or drawing
- doing jigsaw puzzles, crosswords or sudoku puzzles
- knitting or crocheting
- reconnecting with old friends.

At first, many people find it hard to do things that used to bring them joy as they are preoccupied by their cancer. This is very normal, but it will change. By doing things they enjoy and balancing these with things that give them a sense of achievement, they can reduce anxiety and depression, as well as helping them cope better with the side effects of treatment.

## Getting plenty of sleep

People going through treatment for cancer may notice changes in their sleep patterns or have difficulty sleeping. These changes may be caused by the side effects of treatment, medicines you are taking, spending time in hospital or away from home, and stress. But getting enough sleep is important for your physical and mental health. A good night's sleep helps you think clearly, lowers your blood pressure, helps your appetite and strengthens your immune system.

Talk with your health care team if you are having problems sleeping. They can recommend ideas on how to get a better night's sleep.

- ▶ Listen to our *Sleep and Cancer* podcast at [cancercouncil.com.au](http://cancercouncil.com.au)

## Complementary therapies

Complementary therapies focus on the whole person, not just the cancer, and are designed to be used alongside conventional medical treatments such as surgery, chemotherapy and radiation therapy. They may help people cope better with symptoms of cancer and/or side effects caused by conventional treatments. They can increase your sense of control, decrease stress and anxiety, and improve your mood. Some have been scientifically tested and shown to work.

People diagnosed with cancer use complementary therapies for a number of reasons, such as improving quality of life, taking a more active part in their health and strengthening their body to cope with treatment. Some Australian cancer centres have developed “integrative oncology” services where evidence-based complementary therapies are combined with conventional treatments to improve both wellbeing and clinical outcomes.

Complementary therapies are widely used by people with cancer in Australia. Research shows that two out of three people with cancer used at least one form of complementary therapy during or after their cancer treatment.<sup>5</sup> Women are the most common users of complementary therapies.

Let your doctor know about any therapies you are using or thinking about trying, as some may not be safe or evidence based.

► See our *Understanding Complementary Therapies* booklet.



Alternative therapies are therapies used *instead of* conventional medical treatments. These are unlikely to be scientifically tested and may prevent successful treatment of the cancer. Cancer Council does not recommend the use of alternative therapies as a cancer treatment.

Complementary therapy	Clinically proven benefits
<b>acupuncture</b>	reduces chemotherapy-induced nausea and vomiting; improves quality of life
<b>aromatherapy</b>	improves sleep and quality of life
<b>art therapy, music therapy</b>	reduce anxiety and stress; manage fatigue; aid expression of feelings
<b>counselling, support groups</b>	help reduce distress, anxiety and depression; improve quality of life
<b>hypnotherapy</b>	reduces pain, anxiety, nausea and vomiting
<b>massage</b>	improves quality of life; reduces anxiety, depression, pain and nausea
<b>meditation, relaxation, mindfulness</b>	reduce stress and anxiety; improve coping and quality of life
<b>qi gong</b>	reduces anxiety and fatigue; improves quality of life
<b>spiritual practices</b>	help reduce stress; instil peace; improve ability to manage challenges
<b>tai chi</b>	reduces anxiety and stress; improves strength, flexibility and quality of life
<b>yoga</b>	reduces anxiety and stress; improves general wellbeing and quality of life

## Relationships

Cancer and its treatment can cause changes in your life and can affect your relationships with family and friends. Cancer is stressful, tiring and upsetting, and this may strain relationships. If you have a partner, you may worry about changes to your relationship. Or you might worry about starting a new relationship. Even couples who have been together for a long time might worry about the effect of cancer on their relationship.

But cancer may also result in positive changes to your values, priorities, and outlook on life. Going through an experience like cancer can make relationships stronger. Give yourself time to adjust to what's happening and do the same for those around you. Every relationship is different, so it is important to spend time discussing your feelings and finding out what the other person thinks and feels.

► See our *Emotions and Cancer* booklet.

## Sexuality

Cancer can affect your sexuality in physical and emotional ways. The impact of these changes depends on many factors, such as treatment and side effects, your self-confidence, and if you have a partner.

Although sexual intercourse may not always be possible, closeness and sharing can still be part of your relationship.

► See our *Sexuality, Intimacy and Cancer* booklet.

## Contraception and fertility

During treatment for cancer you may have to use contraception to protect your partner or avoid pregnancy for a time. Your doctor will explain what precautions to take. They will also tell you if treatment will affect your fertility permanently or temporarily. If having children is important to you, discuss the options with your doctor before starting treatment.

► See our *Fertility and Cancer* booklet.

# Life after treatment

For most people, the cancer experience doesn't end on the last day of treatment. Life after treatment can present its own challenges. You may have mixed feelings when treatment ends and worry that every ache and pain means the cancer is coming back. Some people say that they feel pressure to return to "normal life" after treatment ends. But recovery is a gradual process. How quickly it takes to get back to doing everyday things depends on your type of cancer, your treatment and your general health. It is important to allow yourself time to adjust to the physical and emotional changes and establish a new daily routine at your own pace.

Cancer Council 13 11 20 may be able to help you connect with other people who have had a rare cancer and provide you with information about the emotional and practical aspects of living well after cancer.

► See our *Living Well After Cancer* booklet.

## Dealing with feelings of sadness

---

If you have continuing feelings of sadness, have trouble getting up in the morning and have lost motivation to do things that previously gave you pleasure, you may be experiencing depression.

Fear of the cancer returning is also a form of anxiety. Talk to your GP, as counselling or medication may help. Some people can get a

Medicare rebate for sessions with a psychologist.

Cancer Council may also run counselling programs in your area. Call 13 11 20 to check. For information about coping with depression and anxiety, call Beyond Blue 1300 22 4636 or visit [beyondblue.org.au](http://beyondblue.org.au). For 24 hour crisis support, call Lifeline 13 11 14 or visit [lifeline.org.au](http://lifeline.org.au).

## Follow-up appointments

After treatment ends, you will have regular check-ups to monitor your health, manage any long-term side effects and check that the cancer hasn't come back or spread. You will usually have a physical examination, tests and scans depending on the type of cancer you had.

Some cancer centres work with patients to develop a “survivorship care plan” which includes a summary of your treatment, sets out a schedule for follow-up care, lists any symptoms and long-term side effects to watch out for, identifies any medical or emotional problems that may develop and suggests ways to adopt a healthy lifestyle. If you don't have a care plan ask your specialist for one and make sure a copy is given to your GP and other health care providers.

How often you will need to see your doctor will depend on the level of monitoring needed for the type and stage of the cancer you had. Your doctor may want to see you two to four times a year for the first year, twice a year for the next few years, and then yearly for a few years. Check-ups will become less frequent if you have no further problems.

It is very important that you attend your appointments. You may feel anxious before an appointment and find yourself thinking more about the cancer and what you went through, but over time your anxiety should become less. Between follow-up appointments, let your doctor know immediately of any symptoms or health problems.

*“I always get anxious before a follow-up appointment, but it does get easier over time.”* MIKE



## Wayne's story

*My duodenal cancer raised its head in the strangest way. I got really itchy and started turning yellow! I thought I must have eaten something that didn't agree with me, so I went to my GP who sent me for some blood tests and a CT scan.*

*The next day I was in hospital having an endoscopy to put in a stent to open my bile duct. Unfortunately, my bile duct was completely blocked!*

*To say the visit from the cast of doctors when I woke up was scary would be an understatement. I went from being jaundiced to being told I most likely had pancreatic cancer with a five per cent chance of survival! I was fit and had run a half marathon only two weeks before.*

*The next two days were a blur with visits from doctors. After more tests and a PET scan it appeared that the cancer was in my duodenum and not in my pancreas. It was a huge relief knowing that I didn't have pancreatic cancer, but I needed major surgery to remove the cancer*

*and stop it spreading. Everything went well. There were some anxious moments when we returned to the oncologist after surgery, fully expecting a course of chemo but I was told it wasn't needed.*

**“As my cancer was so rare, there were no specific protocols to treat it.”** WAYNE

*The relief was quickly followed by disbelief. Why no chemo? As duodenal cancer is so rare there are no specific protocols for treating it. You are treated as if you have bowel cancer. My lymph nodes were clear, so we just monitor from here and have regular check-ups.*

*Physically, I'm now back to where I was before surgery. I still have some occasional problems with my digestion, and we ride the emotional roller coaster of follow-up appointments, but it does get easier over time.*

## What if my cancer returns?

Feeling anxious or frightened about cancer coming back is a common challenge for cancer survivors. For some people, cancer does come back after treatment. This is known as a recurrence. Having a rare cancer, however, does not make you any more likely to have a recurrence than having a more common cancer. It is important to have regular check-ups so that if cancer does come back, it can be found early.

There are several ways you can manage the fear of recurrence.

- Focus on what you can control, e.g. being actively involved in your follow-up appointments and making positive changes to your lifestyle.
- Talk to your specialist about your risk of recurrence and learn more about your type of cancer.
- Psychological interventions specifically addressing the fear of cancer recurrence have been shown to be effective. Ask your GP for more information or call Cancer Council 13 11 20.
- Learn to recognise and manage the signs of stress and anxiety, such as a racing heartbeat or sleeplessness. Manage these in a healthy way, e.g. you could try yoga or mindfulness meditation.
- Speak with a counsellor or psychologist if the fear of recurrence is overwhelming. They may be able to teach you some strategies to help you manage your fears.
- Social support has been found to play a protective role in the fear of recurrence. Joining a support group may help. Spending time with other people who understand your experience and fear is often useful.



- Consider getting involved in a creative activity. Some people find this helpful in working through their emotions and anxieties.
- Not all symptoms are a sign of cancer, they may indicate other health problems, e.g. diabetes, arthritis, high blood pressure.
- Talk to your doctor about how to distinguish normal aches, pain or sickness from cancer symptoms.
- See your GP if you notice any new symptoms or symptoms that have returned. Don't wait for your next check-up.

## Living with advanced cancer

Some people's cancer may be advanced when they are first diagnosed. For others, the cancer may have spread or come back (recur) after treatment (advanced or metastatic cancer). If this happens, there are still treatment options such as surgery, chemotherapy, targeted therapy or radiation therapy to remove the cancer or help control its growth.

Advanced cancer usually can't be cured, but it can often be controlled. This is known as palliative treatment. Sometimes treatment can shrink the cancer, stop or slow the spread of advanced cancer, or relieve side effects. Treatment will depend on where the cancer started, how far and where it has spread, and your general health, treatment goals and preferences. Treatment can help maintain quality of life for several years. In this case, the cancer may be considered a chronic (long-term) disease. Some people join clinical trials to try new treatments.

- ▶ See our *Living with Advanced Cancer* booklet.
- ▶ Listen to our *The Thing About Advanced Cancer* podcast at [cancercouncil.com.au](http://cancercouncil.com.au)

## Palliative care

Palliative care is care that helps people with advanced cancer to live as fully and comfortably as possible. It's sometimes called supportive care. The main goal is to help you maintain your quality of life by identifying and dealing with your physical, emotional, cultural, social or spiritual needs. It involves a range of services offered by doctors, nurses and allied health professionals, such as physiotherapists, dietitians and psychologists, as well as volunteers and carers. Palliative care may be beneficial for people at any stage of advanced cancer – it is not just for end of life.

Palliative care involves a range of services that will be tailored to your individual needs. Services may include:

- relief of symptoms such as pain, breathlessness, nausea and other symptoms
- help organising equipment for home (e.g. wheelchairs, special beds)
- assistance for families and carers to talk about sensitive issues
- links to other services, such as home help and financial support
- support for people to meet cultural obligations
- counselling, grief and bereavement support
- support for emotional, social and spiritual concerns
- referrals to respite care and hospice services.

Your palliative care may be led by your GP or community nurse, or by the specialist palliative care team in your area. The palliative care team will help you work out the best place for your care. This may be at home supported by community palliative care services, in a hospital, at a residential aged care facility or in a palliative care unit (hospice).

► See our *Understanding Palliative Care* booklet

## How palliative treatment can help

---

Medical treatment is a key part of palliative care. It can reduce cancer symptoms, which may include pain, fatigue, nausea and constipation, and can reduce side effects from cancer treatments.

Some examples of palliative medical treatment include:

- chemotherapy or targeted therapy to stop the cancer growing into other organs
- radiation therapy to reduce pain (e.g. if cancer has spread to the bones or a tumour is pressing on nerves or organs)
- surgery to reduce tumours causing pain or other symptoms
- immunotherapy to trigger the body's immune system to fight cancer
- use of a feeding tube to help you get enough nutrition
- medicines to control symptoms and relieve discomfort.

---

## Planning ahead

Planning ahead is important whether you have a serious illness or not. Finding all your personal, financial and legal paperwork and deciding what to do can be difficult. But getting your affairs in order can help you feel more in control of your life and what the future holds, brings a sense of relief, and allows you to focus on treatment and living.

It's helpful to have all of your paperwork up to date and in one secure place. This will make it easier if a family member or friend has to help you with financial and legal matters. Important documents include birth, marriage or divorce certificates, bank and credit card information, passwords, Centrelink and Medicare details, private health insurance details, house title/lease documents, superannuation details, insurance details, investment and loan details, your will and your advance care directive. Discuss your legal arrangements with your family and give them the name of your lawyer.

## Advance care planning

It is a good idea to plan for your future medical treatment and care, and to discuss your preferences and values with your family, friends and health care team. This process is called advance care planning, and it helps ensure that your family and health care team will make decisions that respect your treatment preferences when you are unable to communicate your wishes.

Advance care planning involves:

- appointing a substitute decision-maker to make decisions for you if in the future you lose capacity to make these decisions yourself. Depending on where you live, the documents for appointing this person may be known as an enduring power of attorney, enduring power of guardianship, or appointment of a medical treatment decision maker.
- completing an advance care directive. This is a written record of your instructions for future medical care. Depending on where you live, the document may also be known as an advance health directive or advance personal plan. It only comes into effect if you are unable to make decisions for yourself.

Your advance care documents can be as simple or as detailed as you like. If you have religious or cultural beliefs that may affect your health care decisions, record these in your advance care documents. You need to be an adult and have capacity to complete advance care documents. Advance care planning doesn't mean that you have given up or will die soon – it gives you the security to know that you have planned for the worst and that you can now focus on treatment and living.

- ▶ See [cancercouncil.com.au](http://cancercouncil.com.au) for more information on Advance care planning.

# Seeking support

A cancer diagnosis can affect every aspect of your life, especially when you are diagnosed with a rare or less common cancer. You will probably experience a range of emotions – fear, sadness, anxiety, anger and frustration are all common reactions. Cancer can also create practical and financial issues.

There are many sources of support and information to help you, your family and carers navigate all stages of the cancer experience, including:

- information about cancer and its treatment
- access to benefits and programs to ease the financial impact of cancer treatment
- home care services, such as Meals on Wheels, nurses and home help
- aids and appliances
- support groups and programs
- counselling and psychological services.

The availability of services will vary on a number of factors including your age, the level of assistance required and where you live. To find good sources of support and information, call Cancer Council 13 11 20, get in touch with Rare Cancers Australia 1800 257 600, or talk to the social worker or nurse at your hospital or treatment centre.



Rare Cancers Australia is a charity whose purpose is to improve the lives and health outcomes of Australians living with rare and less common cancers. It focuses on patient support programs, treatment and research, fundraising, and creating a community for people diagnosed with a rare or less common cancer. Visit [rarecancers.org.au](http://rarecancers.org.au) to learn more.

## Support from Cancer Council

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

### Cancer Council 13 11 20



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

### Information resources



Cancer Council produces booklets and fact sheets on more than 25 types of cancer, as well as treatments, emotional and practical issues, and recovery. Call 13 11 20 or visit your local Cancer Council website.

### Legal and financial support



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

### Practical help



Cancer Council can help you find services or offer guidance to manage the practical impacts of cancer. This may include helping you access accommodation and transport services.

### Peer support services



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

## Useful websites

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

### Australia

Cancer Council	See back cover for websites
Cancer Council Australia	<a href="http://cancer.org.au">cancer.org.au</a>
Cancer Council Online Community	<a href="http://cancercouncil.com.au/OC">cancercouncil.com.au/OC</a>
Cancer Council podcasts	<a href="http://cancercouncil.com.au/podcasts">cancercouncil.com.au/podcasts</a>
ANZUP Cancer Trials Group	<a href="http://anzup.org.au">anzup.org.au</a>
Australian Cancer Trials	<a href="http://australiancancertrials.gov.au">australiancancertrials.gov.au</a>
Australian Psychological Society (find a psychologist)	<a href="http://psychology.org.au/find-a-psychologist">psychology.org.au/find-a-psychologist</a>
Beyond Blue	<a href="http://beyondblue.org.au">beyondblue.org.au</a>
Cancer Australia	<a href="http://canceraustralia.gov.au">canceraustralia.gov.au</a>
Carer Gateway	<a href="http://carergateway.gov.au">carergateway.gov.au</a>
Cart-Wheel (Center for Analysis of Rare Tumours)	<a href="http://cart-wheel.org">cart-wheel.org</a>
Department of Health	<a href="http://health.gov.au">health.gov.au</a>
Healthdirect Australia	<a href="http://healthdirect.gov.au">healthdirect.gov.au</a>
Rare Cancers Australia	<a href="http://rarecancers.org.au">rarecancers.org.au</a>
Relationships Australia	<a href="http://relationships.org.au">relationships.org.au</a>
Services Australia (including Medicare and Centrelink)	<a href="http://servicesaustralia.gov.au">servicesaustralia.gov.au</a>

### International

American Cancer Society	<a href="http://cancer.org">cancer.org</a>
Cancer Research UK	<a href="http://cancerresearchuk.org">cancerresearchuk.org</a>
Macmillan Cancer Support (UK)	<a href="http://macmillan.org.uk">macmillan.org.uk</a>



# Caring for someone with a rarer cancer

You may be reading this booklet because you are caring for someone with a rare or less common cancer. What this means for you will vary depending on the situation. Being a carer can bring a sense of satisfaction, but it can also be challenging and stressful.

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

**Support services** – Support services such as Meals on Wheels, home help or visiting nurses can help you in your caring role. You can find local services, as well as information and resources, through the Carer Gateway. Call 1800 422 737 or visit [carergateway.gov.au](http://carergateway.gov.au).

**Support groups and programs** – Many cancer support groups and cancer education programs are open to carers as well as to people with cancer. Support groups and programs offer the chance to share experiences and ways of coping.

**Carers Australia** – Carers Australia provides information and advocacy for carers. Visit [carersaustralia.com.au](http://carersaustralia.com.au).

**Cancer Council** – You can call Cancer Council 13 11 20 or visit your local Cancer Council website to find out more about carers' services.

► See our *Caring for Someone with Cancer* booklet.



# Question checklist

---

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

---

## Diagnosis

- What type of cancer do I have?
  - Where is the cancer located in my body?
  - Has the cancer spread? If so, where to? How fast is it growing?
  - Can you explain the results of the tests to me?
  - I'm thinking of getting a second opinion. Can you recommend another specialist?
  - Is there a patient organisation or support group for the type of cancer I have?
- 

## Treatment

- How many patients with this type of cancer have you treated before?
  - Will the treatment for my rare or less common cancer be different from the more common type of that cancer?
  - What are my treatment options?
  - How long will the treatment take? When will treatment start?
  - What is the aim of the treatment?
  - How will I know if the treatment is working?
  - Are there any out-of-pocket expenses not covered by Medicare or my private health cover? Can the cost be reduced if I can't afford it?
  - What is my prognosis?
  - Are there any complementary therapies that might help me?
  - Are there any clinical trials being done for this cancer that I could join?
- 

## Side effects

- What are the risks and possible side effects of each treatment?
  - How will these be managed?
  - Will I have a lot of pain? If so, what will be done about this?
- 

## After treatment

- How often will I need check-ups after treatment?
  - If the cancer returns, how will I know? What further treatment could I have?
-

# Glossary

---

## **advanced cancer**

Cancer that is unlikely to be cured. In most cases, the cancer has spread to other parts of the body (secondary or metastatic cancer). Treatment can often still control the cancer and manage symptoms.

## **advance care planning**

When a person thinks about their future health care and discusses their wishes with their family, friends and health care team. The written record of these wishes may be known by different names, such as an advance care directive, advance care plan, or “living will”.

## **alternative therapies**

Therapies that are used in place of conventional treatment, often in the hope that they will provide a cure.

## **anxiety**

Strong feelings of fear, dread, worry or uneasiness. Physical symptoms can include racing heart, shallow/fast breathing, shaking, nausea and agitation.

---

## **benign**

Not cancerous or malignant.

---

## **cancer**

Uncontrolled growth of cells that may result in abnormal blood cells or grow into a lump called a tumour. These cells may spread throughout the lymphatic system or bloodstream to form secondary or metastatic tumours.

## **check-up**

A medical appointment involving tests and scans after treatment has finished. Also known as a follow-up.

## **chemotherapy**

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

## **clinical trial**

A research study that tests new approaches to prevention, screening, diagnosis or treatment, to see if they are better than current treatments.

## **complementary therapies**

Any of a range of therapies used alongside conventional treatment to improve general health, wellbeing and quality of life.

---

## **depression**

Very low mood and loss of interest or enjoyment in life, lasting for more than two weeks. It can cause physical and emotional changes.

## **diagnosis**

The identification and naming of a person's disease.

---

## **fatigue**

Extreme tiredness and lack of energy that doesn't go away with rest.

---

## **general practitioner (GP)**

A doctor based in the community who treats all illnesses, referring patients to specialists as needed. Sometimes known as a family doctor.

---

## **immunotherapy**

A treatment that stimulates the body's immune system to fight cancer.

## **insomnia**

Difficulties in getting to sleep or staying asleep, or early morning waking with an inability to return to sleep.

---

## **less common cancer**

In Australia, a type of cancer that has between 6 and 12 incidences per year per 100,000 population.

---

## **malignant**

Cancerous. Malignant cells can spread (metastasise) and eventually cause death if they cannot be treated.

## **metastasis**

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

---

## **palliative care**

The holistic care of people who have a life-limiting illness, their families and carers. It aims to maintain quality of life by addressing physical, emotional, cultural, spiritual and social needs.

## **primary cancer**

The original cancer. Cells from the primary cancer may break away and be carried to other parts of the body, where secondary cancers may form.

## **prognosis**

The expected outcome of a particular person's disease.

---

## **radiation therapy**

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

## **rare cancer**

In Australia, a type of cancer that has less than 6 incidences per year per 100,000 population.

---

## **side effect**

Unintended effect of a drug or treatment.

## **specialist**

A doctor with qualifications and skills in a particular branch of medicine.

## **surgery**

A procedure performed by a surgeon to remove or repair a part of the body.

## **symptoms**

Changes in the body that a patient feels or sees, which are caused by illness or treatment, e.g. pain, tiredness, rash or a stomach-ache.

---

## **tumour**

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

---

## **Can't find a word here?**

For more cancer-related words, visit:

- [cancercouncil.com.au/words](http://cancercouncil.com.au/words)
- [cancervic.org.au/glossary](http://cancervic.org.au/glossary)

---

## **References**

1. Australian Institute of Health and Welfare 2019. *Cancer in Australia 2019*. Cancer series no. 119. Cat no. CAN 123. Canberra: AIHW.
2. Rare Solutions: A Time to Act. *Rare Cancers Australia*, 2017; <https://www.rarecancers.org.au/page/144/rare-solutions-a-time-to-act>
3. Australian Institute of Health and Welfare 2019. *Cancer in Australia 2019. Deaths from rare and less common cancers*. Cancer series no. 119. Cat no. CAN 123. Canberra: AIHW.
4. Australian Institute of Health and Welfare 2019. *Cancer in Australia 2019*. Cancer series no. 119. Cat no. CAN 123. Canberra: AIHW.
5. B Oh et al., "The use and perceived benefits resulting from the use of complementary and alternative medicine by cancer patients in Australia", *Asia-Pacific Journal of Clinical Oncology*, vol. 6, no. 4, 2010, pp. 342-49.



# How you can help

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

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

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

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

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

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

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



# Cancer Council

## 13 11 20

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

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

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

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



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



If you are deaf, or have a hearing or speech impairment, you can contact us through the National Relay Service. [communications.gov.au/accesshub/nrs](https://communications.gov.au/accesshub/nrs)

---

*Cancer Council services and programs vary in each area.  
13 11 20 is charged at a local call rate throughout Australia (except from mobiles).*

For information & support  
on cancer-related issues,  
call **Cancer Council 13 11 20**

## Visit your local Cancer Council website

---

**Cancer Council ACT**  
[actcancer.org](http://actcancer.org)

**Cancer Council Queensland**  
[cancerqld.org.au](http://cancerqld.org.au)

**Cancer Council Victoria**  
[cancervic.org.au](http://cancervic.org.au)

**Cancer Council NSW**  
[cancercouncil.com.au](http://cancercouncil.com.au)

**Cancer Council SA**  
[cancersa.org.au](http://cancersa.org.au)

**Cancer Council WA**  
[cancerwa.asn.au](http://cancerwa.asn.au)

**Cancer Council NT**  
[cancer.org.au/nt](http://cancer.org.au/nt)

**Cancer Council Tasmania**  
[cancertas.org.au](http://cancertas.org.au)

**Cancer Council Australia**  
[cancer.org.au](http://cancer.org.au)

*A web-based resource for Australians with less common cancers project is a Cancer Australia Supporting people with cancer Grant initiative, funded by the Australian Government. [canceraustralia.gov.au](http://canceraustralia.gov.au)*

