

# Living with Advanced Cancer

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



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

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First published January 2003. This edition December 2025.

© Cancer Council Australia 2025. ISBN 978 1 923073 37 1

*Living with Advanced Cancer* is reviewed approximately every three years.

Check the publication date above to ensure this copy is up to date.

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### Acknowledgements

This edition has been developed by Cancer Council NSW on behalf of all other state and territory Cancer Councils as part of a National Cancer Information Subcommittee initiative. All updated content has been clinically reviewed by Dr Lucy Gately, Medical Oncologist, Alfred Health and Walter and Eliza Institute for Medical Research, VIC and Penny Neller, Project Manager, End of Life Law for Clinicians, Australian Centre for Health Law Research, Queensland University of Technology, QLD. This edition is based on the previous edition, which was reviewed by the following panel: Dr Lucy Gately (see above); Dr Katherine Allsopp, Supportive and Palliative Care Specialist, Westmead Hospital, NSW; Prof Megan Best, The University of Notre Dame Australia and The University of Sydney, NSW; Dr Keiron Bradley, Palliative Care Consultant, Medical Director Palliative Care Program, Bethesda Health Care, WA; Craig Brewer, Consumer; Emeritus Professor Phyllis Butow, Psychologist, The University of Sydney and Chris O'Brien Lifehouse, NSW; Louise Durham, Palliative Care Nurse Practitioner Outpatients, Princess Alexandra Hospital, Metro South Palliative Care, QLD; Dr Roya Merie, Radiation Oncologist, Icon Cancer Centre, Concord, NSW; Penny Neller (see above); Caitriona Nienaber, 13 11 20 Consultant, Cancer Council WA; Xanthe Sansome, Program Director, Advance Care Planning Australia, VIC; Sparke Helmore Lawyers; Peter Spolic, Consumer. We would like to thank the health professionals, consumers and editorial teams who have worked on previous editions of this title.

### Note to reader

Always consult your doctor about matters that affect your health, a financial adviser or financial counsellor about matters concerning your finances, and a lawyer about legal matters. 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 booklet 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 may change. Laws, regulations and entitlements that affect people with cancer may change. Cancer Council Australia and its members exclude all liability for any injury, loss or damage incurred by use of or reliance on the information provided in this booklet.

### Cancer Council

Cancer Council is Australia's peak non-government cancer control organisation. Through the 8 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.



*Cancer Council acknowledges Traditional Custodians of Country throughout Australia and recognises the continuing connection to lands, waters and communities. We pay our respects to Aboriginal and Torres Strait Islander cultures and to Elders past and present.*



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# About this booklet

This booklet has been prepared to help you understand more about advanced cancer – a cancer that has spread, come back, or is at a late stage when found (diagnosed).

If cancer spreads beyond where it first started (the primary site), it may be called secondary, metastatic, stage 4 or advanced cancer. Cancer that has come back is called a recurrence or relapse. People may find out they have advanced cancer when it is first diagnosed. We call all these situations “advanced cancer”.

No matter what words are used, it's frightening to hear that cancer has spread, come back or is advanced. This booklet aims to give you practical information about advanced cancer and how it may be treated. It also outlines what to expect and the support that's available to you.

It's okay to read only the chapters that you find helpful. Leave anything too upsetting – you can come back to it later. Some medical terms that may be unfamiliar are explained in the glossary (see page 69). You may like to pass this booklet to family and friends for their information.

**How this booklet was developed** – This information was developed with help from a range of health professionals as well as people affected by advanced 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).



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### **Key to icons**

Icons are used throughout this booklet to indicate:



More information



Alert



Personal story



Tips

### **Is this Cancer Council booklet helpful?**

Please follow this QR code for a quick 3-minute survey, or call 13 11 20 to provide your feedback.



SCAN ME

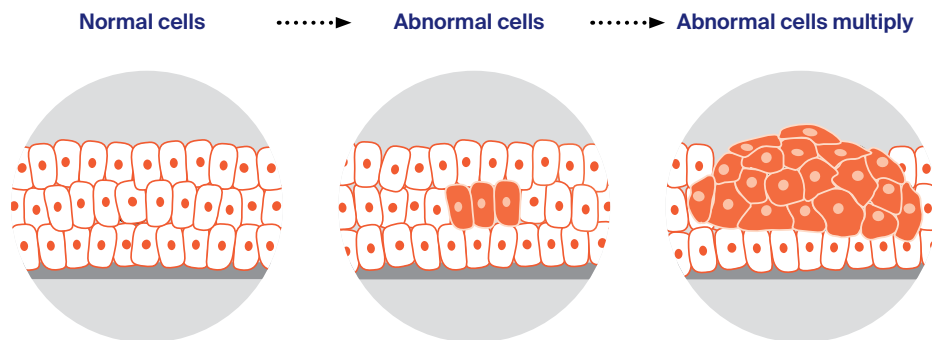
# What is advanced cancer?

Cancer is a disease of the cells, which are the body's basic building blocks. It occurs when abnormal cells divide and multiply in an uncontrolled way. There are many types of cancer and each type develops differently. Some grow slowly, some move rapidly, and others behave unpredictably. While some types of cancer respond well to treatment, other types are more difficult to treat.

The cancer that first develops in an organ or tissue is called the primary cancer. It is considered locally advanced if the tumour is very large or the cancer has spread to nearby tissues.

## How cancer starts

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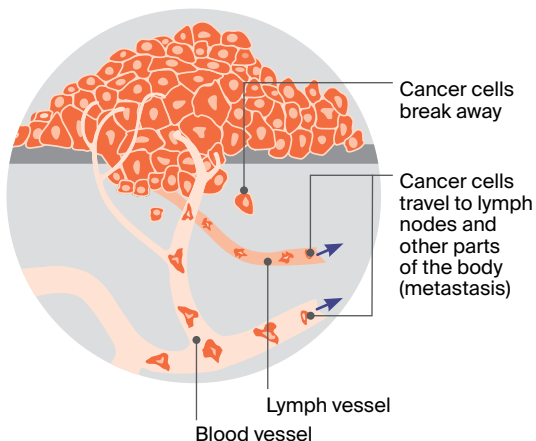
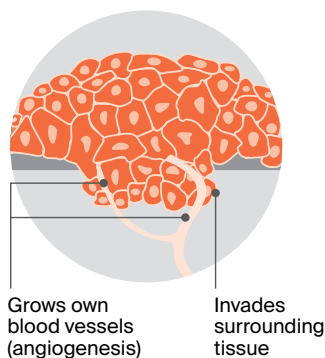


If cancer cells from the primary site break away and travel through the bloodstream or lymph vessels to other parts of the body, they can grow and form another tumour at a new site. This is called a secondary cancer or metastasis. A cancer may spread to any area including the lungs, brain, liver and bones. This metastasis keeps the name of the original cancer. For example, bowel cancer that has spread to the liver is still called metastatic bowel cancer, even though the main symptoms may be coming from the liver. A secondary cancer or metastasis is an advanced cancer.

Although medical treatments usually can't cure advanced cancer, they may slow its growth or spread, sometimes for months or years. Palliative care can help manage cancer symptoms such as pain, and reduce side effects from cancer treatments. Other palliative care services can improve quality of life at any stage of advanced cancer (see pages 36–37).

## How cancer spreads

### .....► Malignant cancer



# Key questions

## **Q: What will advanced cancer mean for me?**

**A:** Although advanced cancer usually can't be cured, it can often be effectively controlled. It's important to realise that incurable doesn't mean untreatable – sometimes treatment can be very effective. Treatment may be able to shrink, stop or slow the spread of advanced cancer. In other cases, it can help to relieve symptoms.

Treatment can often keep the cancer under control and maintain quality of life, sometimes for several years. When this happens, the cancer is considered to be a chronic (long-term) disease.

## **Q: What treatments are available?**

**A:** Your treatment options will depend on where the cancer started, how far and where it has spread to, and whether it is hormone dependent or has certain genetic changes. Your doctor will consider your symptoms and general health and take into account your preferences when recommending treatment.

Treatments to control the cancer and relieve side effects may include chemotherapy, radiation therapy, surgery, targeted therapy, hormone therapy and immunotherapy – used alone or in combination.

Some people join clinical trials to try new treatments (see page 27).

Treatments can be used for different reasons, so talk to your health care team about the aim of each treatment. For further details, see the *Treatment for advanced cancer* chapter on pages 29–41.

## Q: How will advanced cancer affect my day-to-day life?

**A:** Some people with advanced cancer can stay reasonably well and continue usual activities – working, playing sport and socialising – for a long time. Other people may need to focus on their health. It will depend on how you feel, and how cancer or treatment affects various aspects of your life.

**Emotional changes** – Being told that you have advanced cancer, or that the cancer has spread or come back, can have a huge emotional impact. The cancer or treatment can also change how you feel. For example, some hormone treatments directly affect moods. It can also be difficult to cope with the feeling of uncertainty and the stress of changes to your work, finances and relationships. For more information, see *Ways to manage how you're feeling* on pages 12–13.

**Side effects** – The cancer, or its treatment, may cause a range of side effects, such as pain, nausea, fatigue or breathlessness. These can affect what you can comfortably do and your sense of independence. See the *Managing symptoms* chapter on pages 42–52.

**Money concerns** – You or a partner may need time off work, or you may have treatment or other costs that add up. This can lead to worry about money, or a need for financial assistance. For information, see *Dealing with bills and debts* on pages 53–55.

**Practical issues** – There may be ways to make life more comfortable, such as using medical equipment, modifying your home, or getting home help. If you travel a long way from home to the hospital, you may need assistance with transport or somewhere to stay. Call Cancer Council on 13 11 20 to find out about options open to you.

## **Q: Do I need to think about palliative care?**

**A:** Some people feel anxious about having palliative care, or avoid it altogether, because they think it's only for people who are at the end of their life. But that's not the case at all. In fact, studies show that starting palliative care early can help you to feel better for longer.

The goal is to help you maintain your quality of life at any stage of the illness. By offering a range of services and treatment, palliative care can help you live as fully and as comfortably as possible. It does this by looking after your physical, emotional, cultural, social and/or spiritual needs. For example, palliative care can include strategies to help you to manage pain, move around, eat well, and cope with your feelings.

Palliative care, which is sometimes called supportive care, might be something you choose to use now and then, or it may be ongoing. It's now very common for people to use palliative care for several years.

There's a range of health professionals involved in providing multidisciplinary palliative care, from doctors and nurses to physiotherapists, social workers, occupational therapists, dietitians and psychologists – even volunteers and carers.

Thinking about what is most important to you can guide palliative care services. For some people that may be help going travelling; for others it's about spending more time with family. Where possible, help can be provided to focus on what is important to you.

Support for families and carers is also offered through palliative care services. For more information, see pages 36–37.

## Q: What can I expect in the future?

**A:** Not all people with cancer – even advanced cancer – will die from it. For some people, improved treatments can keep advanced cancer under control for months or years. Sometimes other health issues (such as heart disease) become more serious than the cancer.

When told they have advanced cancer, many people will want an idea of how long they may have left to live. Others may prefer not to know or even talk about it. It's a very personal decision. If you want to know the expected outcome (prognosis) of the cancer, talk to your doctor. It is a difficult question to answer because everyone is different. Your doctor can only give you an estimate based on what usually happens to people in your situation. The actual time that you have could be longer or shorter – it's not possible to know for sure.

This not knowing, or feeling of uncertainty, can be one of the most challenging aspects of living with advanced cancer (see page 14).

When faced with the thought of dying, people often think about what they want to do in the time they have left. They may begin to live day by day, plan a big trip or do practical tasks, such as preparing a will. See the *Looking ahead* chapter on pages 53–63.

► See our *Facing End of Life* booklet, and listen to *The Thing About Advanced Cancer* podcast series.

***“The prognosis is based on statistics, and it’s entirely possible that you will be on the good side of those statistics, and make it way beyond whatever your oncologist tells you.”*** JOHN



# The emotional impact

Being diagnosed with advanced cancer can be overwhelming. You might be in shock or feel completely numb. It can be hard to take in any information at this time.

## Common reactions

It's natural to have a lot of different emotions. If you didn't know you had cancer, a diagnosis of advanced cancer can sometimes seem like a double blow. If it's cancer that's come back, you may be more upset than the first time you were diagnosed. Or you may even feel relieved if you suspected there was something wrong, because now you know why.

Everyone reacts differently – especially when told that the cancer is probably too advanced to cure. Give yourself time to absorb what is happening. There is no right or wrong way to react. You might feel one way at first and a completely different way later. It might help to know that your reactions are natural, and that there is support available to manage a range of emotions. Common feelings include:

**Disbelief** – It can be hard to accept that there are limited treatment options or that the cancer can't be cured. While denial can give you time to adjust to reality, if it's ongoing you may delay getting treatment or help. Discuss your diagnosis with your doctor, no matter how you feel.

**Fear or anxiety** – It is frightening to hear that the cancer is advanced when you are diagnosed, or that it has come back or spread. You may be anxious after the shock of diagnosis, or fearful of dying. If these emotions become overwhelming, they may lead to panic attacks.

**Anger** – You may feel angry that you weren't diagnosed earlier, or because you've had to deal with cancer already, or because you feel your life will be cut short. Some people feel angry that, despite leading a healthy lifestyle, they have been diagnosed with cancer. This anger may be directed at family or friends, at doctors, or you may be angry at yourself. Asking "why me?" is completely understandable.

**Guilt** – It's common to blame yourself for the cancer. You may look back at possible symptoms you think you missed, or fear that your lifestyle may have somehow contributed to the cancer. Remember that the reason cancer spreads or doesn't respond to treatment is usually unknown. You may also worry about how your family will cope or feel guilty that they may have to take care of you.

**Uncertainty** – You may have less control over your life and your emotions, and this may leave you feeling helpless or powerless. It can be hard to adjust to an uncertain future or get used to the feeling of not knowing, especially if you are used to being organised or independent.

**Loneliness** – Even if you have people around, you may feel lonely at times. Feeling like nobody understands what you're going through can be isolating. While family and friends are usually supportive, some may have trouble coping with the diagnosis, or misunderstand it. Some people may even distance themselves from you.

**Sadness or depression** – Feeling sad after a cancer diagnosis is a natural response. And your family and friends are often feeling down too. If you have continued feelings of sadness for more than 2-3 weeks, have trouble getting up in the morning or have lost motivation to do things that previously gave you pleasure, talk to your doctor as you may have depression. Support is available for depression.

## Ways to manage how you're feeling

There are some simple things that you can try to help you to cope, or feel more in control, after an advanced cancer diagnosis. Which of these

### Find out more information



Understanding what to expect and being able to plan for any changes can make you feel more in control. Your oncology team (doctors, nurses and allied health practitioners) can give you information and help you to plan.

### Talk about how you're feeling



If you start to feel overwhelmed, let your general practitioner (GP) know. Counselling or medicine – even for a short time – can be helpful. Your GP may be able to refer you for free or subsidised sessions to talk with a psychologist. Beyond Blue also has information about coping with depression and anxiety, which you can find at [beyondblue.org.au](http://beyondblue.org.au).

### Share online



Use email, social media or a blog to stay in touch with family and friends. You can also visit the Cancer Council Online Community at [cancercouncil.com.au/OC](http://cancercouncil.com.au/OC) to connect with others in a similar situation.

### Join a support group



There are some face-to-face, online and phone support groups where people with cancer meet regularly to talk about their experiences. See page 67 for more information about support groups.

strategies works best will be different for everyone, and can change depending on how you are feeling at the time.

### Try complementary therapies



Relaxation, meditation and massage can help you to cope. Complementary therapies can lower your stress levels, ease anxiety, and improve your mood. See page 38 for more information.

### Enjoy the little things



Try to focus on the small things that are still possible – like having a coffee with a friend or visiting your favourite places.

### Accept help



Even when your friends are genuinely willing to help, it can sometimes be hard to ask. You might want one friend or relative to coordinate offers of help and update people on how you are. Online tools can also help organise volunteers, e.g. [gathermycrew.org.au](https://gathermycrew.org.au).

### Draw on spirituality



Some people find meaning and comfort in their religion, faith or spiritual beliefs. Others may experience spirituality in other ways, such as spending time with close family and friends or being out in nature. A cancer diagnosis can sometimes challenge your beliefs. It might help to talk about your feelings with a spiritual care practitioner (sometimes called a chaplain), religious leader or counsellor.

*“Living with uncertainty is the hardest thing. All our friends think ‘We might do this, we might do that in a few years’ and we don’t have that any more. At first that was a huge loss, and we’ve sort of come to terms with that a little bit now, and now we just think very short-term and we don’t plan very far ahead at all.”* SUSAN

## **Coping with advanced cancer**

Whether you’ve just been newly diagnosed or are living with advanced cancer, there will probably be new challenges to deal with, and you may want to explore different ways to help you cope.

### **Managing uncertainty**

Having advanced cancer means not knowing what lies ahead. This can be hard to adjust to – especially if you’re someone who is used to being in control. Some people say they avoid thinking about what the future may hold by keeping busy or distracting themselves from their thoughts. For others, it’s about learning to live with not knowing. There is no right or wrong way to manage this uncertainty.

### **Loss and grief**

A diagnosis of advanced cancer often involves a series of losses – from the loss of good health and changing relationships, to the change of your future plans or a loss of independence. You will probably need time to grieve for these and any other losses.

Different people deal with loss in different ways. It’s not as simple as going through stages or just having a good cry. It is a process, and the

intensity of your feelings can vary. Some people describe different “waves” of grief, from mild to overwhelming. You may experience grief gradually and also at different times – maybe at diagnosis, if you start to feel unwell, or if treatment stops working.

A social worker or counsellor can give you strategies to manage grief and loss. The palliative care team can also provide grief support or refer you to someone who can help. For some people an advanced cancer diagnosis can raise spiritual questions. If this is the case for you, it might help to talk to your religious or spiritual care practitioner.

## **Being realistic**

People with cancer are often told to “stay positive”. And while having hope is important, the reality is that cancer is often frightening and serious. Pressure to “put on a brave face” or be optimistic all the time can drain your energy and stop you saying how you really feel.

Not feeling positive can be a very normal part of having cancer, so try to be realistic about what is happening to you. It can help to talk to someone about how you’re coping and any fears or sadness you have. Being honest with others can help you get support or help if needed.

Sometimes you can tell a counsellor or psychologist worries or thoughts that you might not want to share with family or friends. Your GP can usually refer you to a psychologist for a number of free or subsidised sessions. Ask your GP for a referral to a psychologist or find your own at [psychology.org.au/find-a-psychologist](https://www.psychology.org.au/find-a-psychologist). You can also call Cancer Council on 13 11 20 for help finding someone to talk to. You may be able to access counselling through your cancer treatment centre. Carers can call the Carer Gateway Counselling Service on 1800 422 737 for sessions through their local carers association.

## Looking for meaning

Everyone has different ideas of what gives life meaning. For some people, it might be found in religion or family; for others, it could be found in nature or art. It's common for people diagnosed with advanced cancer to re-evaluate what life means for them.

A diagnosis of advanced cancer does not always stop people from trying to achieve long-held goals, but they may start to focus on what is most important to them. Some people want to live life at a slower pace, others may feel an urgency to make the most of every day.

You may want to discuss meaning in your life with someone close to you, whether that's a spiritual care practitioner, or a professional counsellor or psychologist. If you'd prefer not to talk to anyone, you could write in a journal, meditate or pray.

## Staying hopeful

It can be hard to feel hopeful when you've been told you have advanced cancer. What you hope for may also change with time. You may look forward to good days with understanding people or the love of family and friends. Or you may find yourself hoping you will maintain your sense of independence or stay symptom-free.

Some people try activities they've never tried before and find hope in this new side of their life. Others find hope in small projects, such as completing a scrapbook or planning a trip with their family.

While the cancer and its treatment can limit activities, some people discover new strength in themselves, and this gives them hope. You may find that connecting with other people in a similar situation may also be helpful.

*“If I think of myself as a person who is dying of cancer, then what lies ahead is a hopeless end. If I think of myself as a person who is living with cancer, then my daily life is an endless hope.”* ROBERTA

Faith or spiritual beliefs can provide comfort to some people in tough times. Those who find hope in these beliefs describe feelings of optimism that are hard to explain to others.

Cancer can also test people's beliefs. You may find it helpful to talk to a spiritual care practitioner, counsellor or psychologist about spiritual support.

## **Celebrating life**

Having advanced cancer is often a chance for people to reflect on their life and all that they have done, and to think about their legacy. You could talk with family and friends about the special times you have shared together.

You might like to share some of your belongings with family and friends as a permanent reminder. You could also write letters or stories of your life, record special memories, make a short film or video featuring you with your friends, review or arrange photo albums, document your family's history or family tree, make a playlist of favourite songs, gather treasured recipes into a cookbook, or create artwork or music.



Some people find it helpful to use free online or smartphone apps to track how they're feeling. You might like to try [moodgym.com.au](http://moodgym.com.au), [mindspot.org.au](http://mindspot.org.au) or [thiswayup.org.au](http://thiswayup.org.au).



## Agnes's story

*It was nearly 20 years after my first diagnosis, when the doctors discovered active cancer cells throughout my body, including my lymph nodes and lungs.*

*I had an operation to try to remove cancer from my lungs, but it was too advanced and they couldn't get it all.*

*The doctors told me that the cancer was terminal and I had 6 months left to live. But that was more than 10 years ago, and I'm still here. I feel like I have had cancer for a lifetime: 29 years.*

*I only found out about palliative care a few years ago. For me, this made such a positive difference – I now have equipment such as a walking frame, wheelchair, shower seat and toilet seat.*

*My palliative care nurses visit me at home twice a week and also call a lot to check on me.*

*I have been in hospital many times, but I have been able to stay at home*

*as much as my health has allowed. Being near my family is the most important thing to me.*

*The love I have for my children, and the desire to see them grow up, marry and have kids of their own, has kept me going. I credit them as the reason I've lived with advanced cancer for so long.*

*My advice for someone with advanced cancer is to be strong. Don't be afraid – what will be, will be. Have friends and family around to help provide the support you need. Get all the help you can from government and palliative care services.*

*You need the will, guts and knowledge to make the most of your time. To me, advanced cancer is just a sickness. I don't feel that I'm going to die today. I just take each day as it is, and try to maintain a strong will to live.*



# The people in your life

It can be difficult to tell people you have advanced cancer. You might not want to upset them, or you might not know what to say. Although you may want to protect those you care about, sharing the news can often bring you closer.

It's hard to know how your family and friends will react – and it may not be in a way you expect. Be prepared for different reactions. Sometimes the shock or distress of the news means that people may seem to say the wrong thing, or upset you with how they react. They will probably need time to adjust, and have fears and anxieties, and want information and advice, just like you do.

It's up to you how much detail you share, but delaying the conversation is unlikely to make it any easier. It can be a positive thing to be in control of what information is given out and when, rather than people hearing the news from others.

You may find it helps to practise what you are going to say. Sometimes family members may be more distressed than the person with cancer, which may be hard to cope with alongside your own emotions.

Explain to family and friends how much or how little you want to talk about the cancer, and any other issues you want to discuss.

*“Good communication with my partner was a blessing. It was the total difference in being able to cope.”* KAYE

## **The effect on people close to you**

You may sometimes feel the hardest part about having advanced cancer is the effect on your family and friends. They may need time to come to terms with the prognosis. You may want family to speak to your health care team, especially if they have trouble accepting the news or will be involved in your care and treatment.

### **Partners**

The emotional support provided by a partner can affect how you cope with the diagnosis. Not knowing what the future holds, financial worries, and feeling isolated can challenge a relationship. And partners can feel just as distressed, depressed and anxious as the person with cancer. Being open and honest with each other may help you both cope with sadness and uncertainty, and your relationship may grow stronger.

Differing emotions, ideas or opinions can lead to tension. Your partner may not want to talk about the cancer or may distance themselves to cope. To avoid tension, tell your partner what you need most. Let them know if listening to you is more important than what they say. Explain that you're grateful for their support and you know it's hard for them too. If them doing everything for you is upsetting, tell them that it's important for you to feel involved and independent, even if it's just in small tasks.

### **Changes to your sex life and intimacy**

Humans are sexual beings, and intimacy can add to the quality of our lives and help us to connect. Depending on where the cancer has spread, or the type of treatment you're having, you can feel sore and find even a gentle hug uncomfortable. Your partner may avoid physical contact for fear of rejection, or out of concern that they will cause you pain. It takes time to adapt to physical and emotional changes. Most people find it is easier to re-establish contact by lying close together in bed.

If sexual intimacy is no longer possible or what you want, you may prefer to cuddle, stroke or massage. It can help to talk about your feelings and concerns about any sexual changes in your relationship.

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

## When children take on a caring role

For many families, it's natural to want to look after a parent-figure, or a sister or brother, if they are unwell. This may also be the most practical option if you're unwell. But it also means that your child or sibling may help or care for you in a way that you're not used to.

Being reliant on someone you are used to looking after may be stressful or upsetting. You may feel frustrated or that people are interfering or doing things you never expected them to do. It may seem like an invasion, even if you are grateful for help. Or like you're being told what to do, when you already feel like you have no control. These role reversals can be difficult for both sides. Try to be honest about what you are happy for family to do for you now, and in the future. You can consider home help or talk to a social worker about other options.

## Being a carer

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Anyone who provides care is a carer. Sometimes your family and friends become your carers – even if they don't see it that way. This shift can be confronting for all.

Caring for a person with advanced cancer can be challenging. Even a short break from a caring role, which

is called respite care, can give both of you much needed time out.

The demands on a carer may increase as the cancer advances, so they may need emotional, practical and physical support too.

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

## Talking to children

When you are told you have advanced cancer, one of the biggest worries may be how you will tell the young people in your life. It's natural to want to protect children, but it is also important to let them know what is happening. They will often sense something has changed, and if they aren't told what it is, they can become scared or anxious. Talk to them as soon as you feel ready.

If you've explained cancer and its treatment before, it might be easier to start a conversation. But you might find it hard to talk about the cancer spreading and being difficult to treat. It might be helpful to think ahead about the questions children may ask and prepare some suitable answers.



### How to tell children about cancer

- Be honest and explain what you know about the cancer using straightforward words that suit their age.
- Keep your explanations as simple as possible, and be guided by their questions so you don't offer more information than they may want or can handle.
- Expect that children may respond differently depending on their age. This may range from displays of love and offers of help, to feeling guilty, withdrawal or acting out and bad behaviour.
- Discuss ways your children might be able to help you, while still managing their other commitments or responsibilities.
- Spend time with your children or grandchildren so you can create meaningful memories together.
- See our *Talking to Kids About Cancer* booklet.

## Talking to friends

Friends can be invaluable for emotional and practical support, especially if you're not close to your family or they live far away. Some friends can listen to whatever you say – complaints, hopes, fears – without judging you or trying to cheer you up or give advice. Others may avoid you or not want to talk about the diagnosis.

If friends seem to stay away, they may not know what to say or assume you don't want visitors. Let them know if you want to keep in touch. They may avoid talking about the cancer, worried it will upset you. You could explain if, and how much, you want to talk about it, or if it's okay to just discuss other things. If friends are overprotective or won't leave you alone, it can help to set boundaries to maintain your independence.



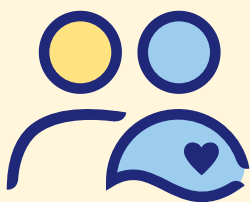
### Conversations with friends

- Set limits around how much you want to share – you can simply say you'd like to talk about something else.
- Ask friends how they feel about the diagnosis – this gives them permission to discuss the situation.
- Be as specific as possible when friends ask how they can help.
- If you don't need particular help from friends or family, let them know that their offer is still appreciated and that you might need something in the future.
- If friends offer information or advice that you're not comfortable with – such as details of an alternative therapy they heard of – change the topic or let them know you are happy with the care provided by your treatment team. You could say that it's something to consider if you are looking to change your treatment.

## Ways to share how you're feeling

Everyone responds to a cancer diagnosis in their own way. How you feel and how you want to communicate that can also change over time and may

### Choose a key contact



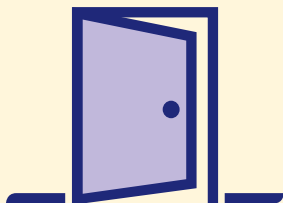
Some people find that having one family member or friend as a central contact person means you don't have to repeat information. You can tell that person what information you are happy for them to share – and what areas you might need some help with – and then they can manage people's concerns along with their offers of help.

### Use technology



There are many ways to keep friends and family updated when you don't have the time or energy to talk with people individually. Use text messages, email, blogs or social media, or write one letter and send copies to friends and family. If you'd like to know what others are up to, then let them know you'd be happy to hear their replies.

### When you don't want to talk



Sometimes you may not want to share your fears and concerns with your family and friends. This is completely normal. You may feel uncomfortable discussing private matters, struggle to find the words to describe your feelings, or worry that you will get upset. Putting things into words can make it seem more real, and you might not feel ready to discuss some things yet. That's okay. Rather than ignoring messages, it can help to let people know if you just don't want to talk at the moment.

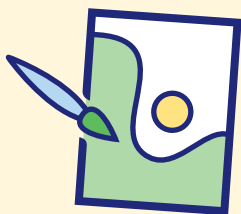
depend on how well you feel or what other things are going on in your life. You might like to share your experience using some of the ideas below.

## Have open conversations



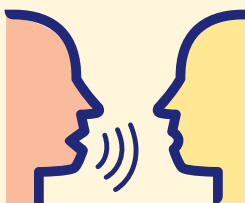
Some family and friends seem to know when you need to share your feelings, and just when to be there for you. But not everyone can tell when you are having a bad day or need to talk – it may be confusing when there may be days you don't feel like sharing at all and others that you do. It can help to be open, honest and direct about when you need to share, and what you need most. For example, a text saying you'd like to talk on the phone and is now a good time, or asking if you can catch up in person as you need a hug and someone to listen more than a big conversation.

## Get creative



You can explore your feelings by writing in a journal, creating artwork or composing a song. You can choose whether to share your work or keep it to yourself, or save it as a gift for someone at a later time.

## Join a support group



Talking about your fears and concerns with people who are going through a similar experience can often be easier. Consider joining a support group, talking to a health professional or calling Cancer Council on 13 11 20 to talk to a nurse or counsellor.



# Making treatment decisions

It can be difficult to decide what treatment to have for advanced cancer. Some people choose treatment even if it offers only a small benefit for a short period of time. Others decide not to have active treatment for the cancer, but to treat symptoms to reduce discomfort and maintain quality of life. What you decide may change over time.

You may want to think about what quality of life means to you and the impact of treatment. Perhaps you would choose chemotherapy if it meant you could have two good weeks each month. Or it might be more important to you to spend as much time as possible with family and friends, without the disruption of tests, treatment or hospital visits.

**Know your options** – Understanding the disease, available treatments, possible side effects and any extra costs can help you weigh up the options and make a well-informed decision. It can also help you feel more in control to have all the information you can about the diagnosis.

**Record the details** – When your doctor first says you have advanced cancer, you may not remember everything you are told. Taking notes may help. If you would like to record the discussion, ask your doctor first. It's a good idea to have a family member or friend come to appointments to join in the discussion, write notes or simply listen.

**Ask questions** – If you are confused or want to check anything, it is important to ask your specialist questions. Try to prepare a list before appointments (see page 68 for 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 a second opinion from another specialist to confirm or clarify what your specialist has said, or to know you have explored all 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 them. You can get a second opinion even if you’ve started treatment or still want to be treated by your first doctor. You may decide to be treated by the second specialist.

**Talking about treatment decisions** – Discussing the kind of care you might want in the future can be difficult. But talking to your family about this can help them if you become too sick to make decisions and they need to make decisions about your health care. To help you reflect on your preferences for care and ways to talk about them with your family, search for Palliative Care Australia’s “discussion starters” at [palliativecare.org.au](http://palliativecare.org.au), and Advance Care Planning Australia’s “talking with family and loved ones” at [advancecareplanning.org.au](http://advancecareplanning.org.au).

## Should I join a clinical trial?

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Your doctor or nurse may suggest you take part in a clinical trial. Doctors run clinical trials to test new or modified treatments and ways of diagnosing disease to see if they are better than current methods. For example, if you join a randomised trial for a new treatment, you will be chosen at random to receive either the best existing treatment or the modified new treatment. Over the years, trials have improved treatments and

led to better outcomes for people diagnosed with cancer.

You may find it helpful to talk to your specialist, a 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.

## **If treatment seems too much**

It can feel worth it to deal with side effects for long-term survival. But if this is unlikely, some people don't want treatments that leave them exhausted or sick. Others choose treatment with significant side effects even if it gives only a small benefit for a short period of time.

- Before you start or stop treatment, think about the benefits, risks and burdens. Decisions rarely have to be made immediately.
- Ask yourself if you are feeling unwell from the treatment side effects, the cancer or the emotions of the diagnosis. Some or all of these may be treatable, and you may have a different outlook if you feel better.
- Check with your health care team whether your treatment can be adjusted to limit side effects.
- Speak to professionals, such as your doctor, a counsellor or social worker, who can help you decide what is important to you.

## **Refusal of medical treatment**

If you are well enough to make clear decisions (called having capacity), you have the right to refuse any treatment offered, even if it goes against your doctor's recommendation. Your medical team will usually still explain the proposed treatment and what will happen if you don't have it. You can stop each treatment separately and at any time – you do not have to accept treatment on an all-or-nothing basis.

In all states and territories, you can complete an advance care directive that your health care team (nurses, doctors, paramedics, etc) must follow. This is a legal document in which you can give instructions about future medical treatment, including any treatment that you do not want to have. It will apply if you get too unwell (lose capacity) to make decisions.

If you have capacity, you can also appoint a substitute decision-maker to make treatment decisions if you become unable to. See pages 55–57.



# Treatment for advanced cancer

The aim of treatment for advanced cancer is to control the cancer for as long as possible. This might mean shrinking the size of the cancer or slowing its growth for a while. In some cases, this may be for months or years. If treatment is no longer controlling the cancer, the aim may be to help relieve the physical and emotional symptoms of cancer. Your doctor will discuss your options and involve you in decisions about the best treatment for your situation. This is called shared decision-making.

New treatments may become available, so if your current treatment stops working or it's hard to cope with side effects, ask your doctor what else you can try or if you're eligible for a clinical trial (see page 27).

Treatment choices for advanced cancer will depend on where the cancer started and how much it has spread. Usually cancer that has spread needs systemic treatment. This means treatment is taken by mouth (orally) or injected into the bloodstream to reach cancer cells throughout the body. Examples include chemotherapy, targeted therapy, immunotherapy and hormone therapy. Treatment that affects only a certain part of the body may also be used to control the cancer or to relieve symptoms. Examples include surgery and radiation therapy.

Often these treatments will be discussed with a range of health professionals (listed on the next two pages) at what is known as a multidisciplinary team (MDT) meeting. You are likely to see a number of health professionals who specialise in different aspects of your care.

- See our information on chemotherapy, surgery, radiation therapy, immunotherapy, targeted therapy, heart health and palliative care.

## Health professionals you may see

|                                  |                                                                                                                                                                                                   |
|----------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>general practitioner (GP)</b> | assists you with treatment decisions and works in partnership with your other specialists in providing ongoing care                                                                               |
| <b>medical oncologist</b>        | treats cancer with drug therapies such as chemotherapy, targeted therapy, immunotherapy and hormone therapy (systemic treatment)                                                                  |
| <b>radiation oncologist</b>      | treats cancer by prescribing and overseeing a course of radiation therapy                                                                                                                         |
| <b>radiation therapist</b>       | plans and delivers radiation therapy                                                                                                                                                              |
| <b>surgeon</b>                   | surgically removes tumours and performs some biopsies; specialist cancer surgeons are called surgical oncologists                                                                                 |
| <b>haematologist</b>             | diagnoses and treats diseases of the bone marrow, blood and lymphatic system; prescribes chemotherapy and other drug therapies                                                                    |
| <b>nurse</b>                     | administers drugs and provides care, information and support throughout treatment; may be a community nurse (see below), specialist palliative care nurse or a palliative care nurse practitioner |
| <b>community nurse</b>           | visits you at home to supervise medical care, assesses your needs for supportive care, and liaises with your GP and MDT as required                                                               |
| <b>pain medicine specialist</b>  | treats all types of pain, particularly severe or difficult pain                                                                                                                                   |
| <b>pharmacist</b>                | dispenses medicines and gives advice about dosage and side effects                                                                                                                                |

|                                                                   |                                                                                                                                                                                                                          |
|-------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <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) |
| <b>palliative care specialists and nurses</b>                     | work closely with your GP and cancer team to help control symptoms and maintain quality of life                                                                                                                          |
| <b>dietitian</b>                                                  | helps with nutrition concerns and recommends changes to diet during treatment and recovery                                                                                                                               |
| <b>physiotherapist and exercise physiologist</b>                  | help restore movement and mobility, and improve fitness and wellbeing                                                                                                                                                    |
| <b>occupational therapist</b>                                     | assists in adapting your living and working environment to help you resume usual activities during and after treatment                                                                                                   |
| <b>counsellor, psychiatrist, psychologist</b>                     | help you manage your emotional response to diagnosis and treatment                                                                                                                                                       |
| <b>spiritual care practitioner (pastoral carer or chaplain)</b>   | discusses any spiritual matters and helps you reflect on your life and search for meaning, if appropriate; may arrange prayer services and other religious rituals                                                       |
| <b>Aboriginal and Torres Strait Islander health practitioners</b> | provide cultural and other support for Aboriginal and Torres Strait Islander peoples with cancer and their families                                                                                                      |
| <b>speech pathologist</b>                                         | helps with communication and swallowing during and after treatment                                                                                                                                                       |
| <b>social worker</b>                                              | links you to support services and helps you with emotional, practical and financial issues                                                                                                                               |

## Chemotherapy

Chemotherapy is the most commonly used treatment when cancer has spread. It circulates throughout the body to affect cells that divide rapidly such as cancer cells. It can kill cancer cells or slow their growth.

There are many types of chemotherapy drugs, and these are often used in different combinations and strengths. Treatment is usually given over a few hours or days, followed by a rest period of 1–4 weeks. Most people have several cycles of treatment. Chemotherapy drugs are usually given by injection or drip into a vein (intravenously) in hospital, but some can also be taken as tablets or capsules (orally) at home.

**Side effects** – Some chemotherapy drugs can cause tiredness, bowel changes, nausea and hair loss. Most side effects are temporary and can be prevented or reduced. Different types of chemotherapy drugs have different side effects – for instance, not all of them cause hair loss.

## Hormone therapy

Some cancers grow in response to particular hormones. These cancers are known as hormone-dependent cancers. Hormone therapy (also called endocrine therapy) uses synthetic hormones to block the effect of the body's natural hormones. The aim is to lower the amount of hormones the tumour receives. This can help slow down the spread of the cancer.

If you have breast or uterine cancer, you may be offered hormone therapy. If you have prostate cancer, the therapy is known as androgen deprivation therapy (ADT).

**Side effects** – Common side effects include tiredness, hot flushes, mood changes, osteoporosis, weight gain and sweating. Other side

effects may impact your sex life, including changes in sex drive, trouble getting or keeping erections or vaginal dryness. Hormone therapy can also affect your fertility. It may bring on menopause symptoms in females. If you have already been through menopause, hormone drugs called aromatase inhibitors may be used.

## Targeted therapy

Targeted therapy is a drug treatment that targets specific features of cancer cells to stop the cancer growing and spreading. The drugs circulate through the body like chemotherapy, but they work in a more focused way and may have fewer side effects than chemotherapy.

Targeted therapy has led to improved survival rates for people with some types of cancer. These drugs are becoming an important part of cancer treatment and may help:

- after surgery to destroy any remaining cancer cells
- to treat advanced cancer that hasn't responded to other treatment, or cancer that has come back
- as maintenance treatment for advanced cancer.

Targeted therapy drugs often cause the signs and symptoms of cancer to reduce or disappear. This means many people can return to their usual activities. The drugs may need to be taken long term, and you will need to have regular tests to monitor the cancer.

Some targeted therapy drugs have been approved for use in Australia for the treatment of a range of cancers including bowel, breast, cervical, kidney, liver, lung, ovarian, stomach and thyroid, as well as melanoma and some forms of leukaemia, lymphoma and myeloma. Targeted therapy has been effective in treating some people with these cancers, but it may not be the best treatment for everyone with advanced cancer.

The Pharmaceutical Benefits Scheme (PBS) subsidises the cost of some targeted therapy drugs for certain cancers. Targeted therapy drugs not on the PBS are usually expensive, but you may be able to have them as part of a clinical trial (see page 27).

**Side effects** – These vary depending on the targeted therapy used, but may include fevers, sensitivity to the sun, rashes, headaches, diarrhoea, bleeding and bruising, and blood pressure changes.

## Immunotherapy

This is a type of drug treatment that uses the body's own immune system to fight cancer cells. Different types of immunotherapy work in different ways. The most commonly used drugs are called checkpoint inhibitors. These drugs help the immune system to bypass “checkpoints” set up by the cancer that block the immune system. They often need to be taken for a long period of time.

Checkpoint inhibitors are currently available in Australia for some types of cancer. They have worked well for some people, but they don't help everyone and it can be difficult to predict whether they will work in certain situations. New immunotherapy drugs are being developed – talk to your doctor about whether any are suitable for you.

**Side effects** – Immunotherapy can cause inflammation in different parts of the body, for example, in the lungs (causing shortness of breath), bowel (causing diarrhoea) or thyroid gland (leading to abnormal thyroid hormone levels). Skin inflammation or rashes are more common. Side effects of immunotherapy need to be reported to your doctor as they may be serious. Some side effects that might be okay after chemotherapy may not be okay after immunotherapy.

## Surgery

Surgery may not be able to remove all cancer cells, but may be used to:

- remove tumours from affected areas, such as the bowel or lymph nodes
- relieve pain and discomfort caused by tumours that stop organs working properly or are pressing on nerves
- improve outcomes from chemotherapy and radiation therapy by reducing tumour size
- insert a thin, hollow tube (stent) into a blocked organ to create a passage for substances to pass through.

## Radiation therapy

Also known as radiotherapy, radiation therapy uses a controlled dose of radiation, such as x-rays, to kill cancer cells or damage them so they cannot grow, multiply or spread. It can be precisely targeted at cancer sites in your body. Treatment is carefully planned to have the greatest effect on the cancer cells and limit damage to healthy body tissues.

Radiation therapy can often shrink tumours or stop them from spreading further. It can also relieve some symptoms, such as bleeding from the tumour or pain from secondary cancer in the bones. Different types of external beam radiation therapy and sometimes internal radiation therapy (brachytherapy) are used depending on the location of the cancer.

**Side effects** – Common side effects include fatigue, skin problems and loss of appetite. These may be temporary or longer lasting. Side effects from radiation depend on the area being treated, for example, skin reactions over the area or tummy upset after radiation to the abdomen. For most people, there is some level of fatigue when having radiation treatment and this may be something to consider.

## Having palliative care

Many people fear hearing the words palliative care because they think it is just for people who are dying, but it's not. Palliative care is useful at all stages of

### What is palliative care?



Palliative care is person-centred care that helps people with a progressive life-limiting illness to live as fully and as comfortably as possible. Palliative care can link you with support. For example, you may need help to move around your home more safely. The main goal is to maintain your quality of life by identifying and meeting your physical, emotional, cultural, social and spiritual needs. Palliative care also provides support to families and carers.

### Who is in a palliative care team?



Your palliative care may be led by your GP or community nurse, or by the specialist palliative care team in your area. The team may include doctors, nurses, social workers, physiotherapists, occupational therapists and spiritual care practitioners. They may also link you to a counsellor, psychologist or other health professionals.

### Where is palliative care usually given?



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 hospital, at a residential aged care facility or in a palliative care unit (hospice). Many services – including things like pain relief – are now available to you at home.

advanced cancer, and involves a range of services that can help with lots of things like pain management or getting around more easily.

## How can palliative care help?



Palliative care involves a range of services that will be tailored to your individual needs. There are various ways it can help, including:

- relief of pain, breathlessness, nausea and other symptoms
- help organising equipment for home (e.g. wheelchairs, special beds)
- links to other services such as home help and financial support
- counselling, grief and bereavement support
- referrals to respite care services
- volunteer services trained in palliative care.

## When can I start?



Depending on your needs, you may use palliative care services occasionally or continuously, for a few weeks or months. The number of people receiving palliative care for several years is increasing. Contacting the palliative care team early means that you can find out what the different team members do and see which services might be useful now or in the future. This will vary according to how you feel, what problems you have, and how your carers are managing.

## Where to find out more



For information about palliative care and how it may be able to help you, visit [palliativecare.org.au](http://palliativecare.org.au), and see our *Understanding Palliative Care* booklet. To find a palliative care service in your local area, search the online directory – or you could speak to your doctor or nurse.

## Complementary and alternative therapies

It's common to wonder whether there are any other therapies you could try. You may want help managing the symptoms and side effects of conventional cancer treatment, such as fatigue, nausea or pain. Some people use therapies to help feel some control over their treatment.

### What are complementary therapies?

Complementary therapies are treatments used alongside conventional cancer treatments, such as chemotherapy or radiation therapy, to improve general health and wellbeing. Check with your doctor if you are unsure about a particular complementary therapy.

Research has shown that some complementary therapies may help people manage the various emotional and physical effects of cancer and its treatment. Examples include:

- **anxiety** – meditation, relaxation, mindfulness, counselling, support groups, art therapy, music therapy, massage, hypnotherapy
- **fatigue** – meditation, relaxation, exercise
- **pain** – hypnotherapy, acupuncture, visualisation, massage, reflexology, acupressure, meditation, relaxation
- **stress** – meditation, relaxation, counselling, support groups, spiritual practices
- **nausea and vomiting** – acupuncture, hypnotherapy.

Cancer treatment centres and palliative care services may offer free therapies (e.g. art therapy, massage, meditation). Some community centres offer group therapies, such as tai chi or yoga, for free or for a small charge. Often you will see a private practitioner and pay for most complementary therapies. If you have private health insurance, check if it provides a rebate for visits to a private practitioner.

► See our *Understanding Complementary Therapies* booklet.



Let your doctor and pharmacist know if you plan to use any complementary or alternative therapies to make sure they do not result in harmful side effects or interfere with other medicines you are taking.

## Alternative therapies

Alternative therapies are commonly defined as treatments used instead of conventional medicine. Many alternative therapies have not been scientifically tested, so there is no proof they stop cancer growing or spreading. Others have been tested and shown not to work.

When cancer has spread and treatment options are limited, some people consider alternative therapies. Friends and family may also suggest that you try alternative treatments. While side effects of alternative therapies are not always known, some can be harmful – for example, taking high-dose vitamins can have side effects, and eliminating food groups could mean that your diet no longer provides all the nutrients you need. Some alternative therapies may be expensive, and they could affect management of your symptoms.

Be suspicious if any treatment:

- claims to cure all cancers
- requires you to travel overseas
- says the medical/pharmaceutical industry wants to stop its use
- suggests it has positive results with few or no side effects.

Cancer Council does not recommend the use of alternative therapies as a treatment for cancer. The Australian Competition and Consumer Commission tracks health and medical scams to help the public detect and avoid scams. To find out more, visit [scamwatch.gov.au](http://scamwatch.gov.au).

## Rehabilitation

Sometimes cancer can limit your activities. Rehabilitation, or rehab, is a way of improving your quality of life between or after treatments. It helps restore your movement and other functions through physiotherapy, occupational therapy, speech therapy or artificial body parts (prostheses). It can also include emotional support, such as counselling.

Returning to work is another form of rehabilitation. You may find you need to start back at work with reduced hours. If you can no longer work, or choose not to, it may be helpful to find another activity that helps you feel involved in life and connected with people.

For many people, rehabilitation is organised through their treatment centre. If you have been treated in a private hospital, ask your doctor about these services. Your GP or palliative care service can also organise rehabilitation for you.

For more information on the availability of rehabilitation services in your area, contact Cancer Council 13 11 20.

*“I had to accept that I was dealing with fatigue and celebrate small improvements. I had to be careful not to overdo it and whatever help people offered, I took. That was very challenging for me but it helped.”* SUSAN

## Key points about treating advanced cancer

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|                       |                                                                                                                                                              |
|-----------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Treatment goal</b> | Treatment aims to control the cancer, slow down its spread and manage any symptoms. This might help you to feel as well as possible for as long as possible. |
|-----------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------|

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|                          |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
|--------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Common treatments</b> | <p>There are different types of treatment for advanced cancer that may be used separately or in combination.</p> <ul style="list-style-type: none"><li>• Chemotherapy is the most commonly used treatment when cancer has spread.</li><li>• Hormone therapy is used for cancer that grows in response to hormones. It can slow tumour growth.</li><li>• Targeted therapy attacks specific features of cells to stop the cancer growing and spreading.</li><li>• Immunotherapy uses your own immune system to attack the cancer.</li><li>• Surgery can be used to remove tumours that might be causing pain.</li><li>• Radiation therapy can shrink tumours or stop them spreading further. It can also relieve some symptoms, such as pain from secondary cancer in the bones.</li><li>• Palliative care helps you manage the symptoms of cancer and the side effects of treatment, and can help maintain your quality of life. Contacting a palliative care team early means that you can find out what may help now and in the future.</li></ul> |
|--------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

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|                        |                                                                                                                                                                                                                                                                                                                        |
|------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Other therapies</b> | <ul style="list-style-type: none"><li>• Some complementary therapies can help reduce side effects such as fatigue and pain.</li><li>• Cancer Council does not support the use of alternative therapies.</li><li>• Rehabilitation is another way of improving your quality of life during or after treatment.</li></ul> |
|------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

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# Managing symptoms

People with advanced cancer can have a range of symptoms. The suggestions in this chapter may help you to find some relief.

## Sleeping problems

Getting enough sleep can help keep up your energy levels and improve your mood. Difficulty sleeping may be caused by pain, breathlessness, anxiety or depression. Some medicines, hormonal changes and nausea can also affect sleep. If you already had sleep problems before the cancer spread, these can become worse. Talk to your doctor about whether your medicines need adjusting or sleep medicines may be an option.



### Ways to improve sleep

- Try some gentle activity each day. A physiotherapist or exercise physiologist can plan an exercise program, and an occupational therapist can suggest equipment to move safely.
- Avoid drinking alcohol, having caffeine, smoking, and eating spicy food.
- Try not to use your TV, computer or smartphone before bed as the blue light may tell your body it's time to wake up.
- Follow a regular bedtime routine and set up a calm sleeping environment.
- Keep the room dark, quiet and at a comfortable temperature.
- Relax with gentle music, rain sounds or Cancer Council's *Finding Calm During Cancer* podcast series before bed.
- If you can't sleep, get up and sit on the couch until you feel sleepy again.
- ▶ Listen to our "Sleep and Cancer" podcast episode.

# Fatigue

Cancer treatments like chemotherapy or radiation therapy, and pain medicines, antidepressants and sedatives, can cause fatigue (tiredness). The cancer, infections or anaemia (low red blood cells) can also cause fatigue, as may loss of weight and muscle tone, insomnia and anxiety or depression. Tell your doctor or nurse if you feel weaker or more tired as there may be ways to help. For example, if you have anaemia, it can be managed with medicines. An occupational therapist can give you equipment to make tasks easier and show you how to save your energy.

► See our *Understanding Fatigue and Cancer* fact sheet.



## Tips to help with fatigue

- Plan activities for when you feel less tired, and include rest breaks.
- Do regular gentle activities, like walking to the letterbox, doing stretches or getting out of bed for meals.
- Avoid stress where possible – relaxation techniques or meditation can help. Listen to the relaxation and meditation recordings in our *Finding Calm During Cancer* podcast series.
- Have short naps rather than one long rest during the day.
- Alcohol can cause tiredness and energy loss, so consider whether you want to drink.
- Use Meals on Wheels or other home delivery meal companies or buy frozen or ready-to-eat meals.
- Delegate some tasks or speak to an occupational therapist about equipment to assist with activities (e.g. a shower chair, a commode).
- Apply for a disability parking sticker to reduce how far you need to walk when going to the hospital or shops.
- Limit visitors if you find they are tiring you.
- Prioritise important activities or those that you feel enrich your wellbeing.

## Pain

Many people with advanced cancer worry they will be in pain, but not everyone has pain. Those who do have pain may not be in pain all the time – it may come and go. The pain may be caused by the cancer itself or by cancer treatment. For example, the tumour may be blocking an organ or pressing on organs, nerves or bone.

If you do experience pain, it can usually be controlled. Pain management is a specialised field, and palliative care teams are trained in finding you the right medicine, dosage and way to take it.

There are many ways to relieve pain, including:

- pain medicines (see opposite page)
- pain-relieving procedures for nerve pain (see opposite page)
- complementary therapies such as massage, meditation, relaxation, acupuncture or hypnotherapy (see page 38)
- chemotherapy, radiation therapy or surgery (see pages 32 and 35).

Everyone experiences pain differently, so it may take time to find the pain relief or combination of treatments that work best for you. Using a pain scale or pain diary can help you describe your pain and how it is affecting you. This will assist your pain specialists to work out the best way to control the pain.

How and where the pain is felt and how it affects your life can change. Regular reviews by pain management experts can usually keep the pain under control. It's better to take medicine regularly as prescribed, rather than waiting for the pain to build up. This is called staying on top of the pain. Your doctor will give you instructions on when to take your medicine. Controlling the pain may allow you to continue with activities you enjoy for some time and offer a better quality of life.

## Types of pain medicines

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Medicines that relieve pain are called analgesics (or pain medicines, pain relievers or painkillers). Some people worry about becoming addicted to pain medicines, but this is unlikely when they are taken palliatively.

Your health care team will monitor you to avoid potential side effects, such as constipation or drowsiness, which can usually be managed.

Depending on the type of pain you have and how intense it is, you may be offered:

- mild pain medicines, such as paracetamol or non-steroidal anti-inflammatory drugs (NSAIDs)
- moderate pain medicine, such as codeine
- strong pain medicine, such as the opioids morphine, hydromorphone, oxycodone and fentanyl.

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## Other ways to control pain

Surgery may help to remove or reduce a tumour, or treat blockages causing pain. Chemotherapy may shrink or slow the growth of a tumour. And radiation therapy may also shrink a tumour, and can help relieve pain if cancer has spread to the brain, bones or other organs.

You may have other types of medicine – for example, antidepressants and anticonvulsants for nerve pain; anti-anxiety drugs for muscle spasms; or local anaesthetics for nerve pain.

If the pain is hard to control, a pain specialist may consider a nerve block. The type of nerve block you are offered will vary depending on the type of cancer. Delivering pain medicine directly into the nerves in the spine via a tube (epidural) usually gives short-term relief. Most medicine that can be given by injection can also be connected to a pump.

- See our *Understanding Cancer Pain* booklet, and listen to the “Managing Pain when Cancer Is Advanced” podcast episode.

## Feeling sick

People with advanced cancer often have problems with feeling sick (nausea) or being sick (vomiting). These can be caused by treatment with chemotherapy or radiation therapy, cancer growth, blockage in the bowel or the location of the cancer. Nausea can usually be managed with medicines. See the opposite page for some things you can do to manage nausea and vomiting.

Many people talk about anticipatory nausea, the response your body learns when you know it is chemotherapy time again. Even if you are no longer having chemotherapy, you may still feel a surge of nausea if you are reminded about chemotherapy – for example, if you go past the place where you were treated or eat a food you ate during that time.

**Blockage in the bowel** – Sometimes cancer in the abdominal area or near the bowel can cause the bowel to become blocked. This is called bowel obstruction. Because waste matter (faeces or poo) cannot pass through the bowel easily, symptoms may include feeling sick or vomiting. To relieve these symptoms, you may have a small, hollow tube (stent) put in that helps keep the bowel open. The stent is inserted through the rectum using a flexible tube called an endoscope. If you have any symptoms of a possible bowel obstruction, seek medical help urgently, don't wait for it to get better.

*“During treatment I developed an active sense of smell. I hated certain smells and did all I could to avoid them. My mouth felt very dry, which made food taste unappetising. Adding extra sauce helped.”* HELEN



## Tips for when you're feeling sick

- Eat small meals or have some snacks 5–6 times throughout the day. While you might not feel like eating, going without food for long periods can make nausea worse.
- Choose cold foods or foods at room temperature, such as sandwiches, salads, stewed fruit or jelly.
- Have some foods or drinks that contain ginger, such as ginger ale, ginger tea or ginger biscuits.
- Take any anti-nausea medicines as prescribed. Let the doctor know if the medicines don't seem to be working as there may be other options you could try.
- Avoid fried, greasy or spicy foods or those that have strong smells.
- Try to reduce stress with meditation. Cancer Council has relaxation and meditation recordings in the *Finding Calm During Cancer* podcast series.

**High levels of calcium in the blood** – Feeling nauseous may be a symptom of high levels of calcium in your blood (hypercalcaemia). If the cancer spreads to the bones, the cancer cells make the bone break down and release calcium into the blood. This can cause you to feel tired, thirsty and confused. Hypercalcaemia is more common in some types of advanced cancer. Drinking more water can sometimes help. You may also be given drugs to lower your calcium levels. These are called bisphosphonates, which are usually given through a drip into a vein.

**Increased pressure in the brain** – Cancer in the brain can also cause nausea. You will usually be given steroids to reduce swelling around the tumour.

## Loss of appetite

People with advanced cancer often notice changes in their appetite. This may be because of the cancer itself, treatment, or other side effects such as tiredness, nausea or vomiting, taste changes, pain, lack of activity, or depression.

Eating helps to maintain strength, function and quality of life. And a loss of appetite can lead to weight loss and malnutrition. Forcing yourself to eat can feel uncomfortable or cause vomiting and stomach pain. See the tips opposite for ways to improve your appetite.

Food-type nutritional supplements can increase nutrient intake. These are used as snacks between meals. Many pharmacies and supermarkets sell these specially formulated nutritional supplements. You do not need a prescription, though it may be cheaper if you have one from a doctor or dietitian. Your health care team may suggest a brand to try.

People with advanced cancer may develop a muscle-wasting syndrome known as cachexia. This means the body isn't using protein, fats and carbohydrates properly. Your doctor or dietitian will discuss ways to manage cachexia, which may include nutritional supplements or medicines such as appetite stimulants.

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

*“It was very important for our family and friends to be well informed about the ongoing problems with eating and digestion that occur during surgery. Having support helped us adjust to the changes.”* JOHN



## Ways to help improve appetite

- Good nutrition can improve quality of life, but if you're not feeling hungry then it's okay to focus on eating foods that you enjoy to help stimulate your appetite.
- Eat what you feel like, when you feel like it. Don't worry so much about timing or set meal times. You could have something lighter like cereal for dinner or a main meal at lunch.
- Use a smaller plate – a big plate full of food may put you off eating.
- Relax dietary restrictions. With advanced cancer, maintaining your weight is more important than avoiding full-fat foods like whole milk or yoghurt.
- Add flavour to foods with lemon or lime juice, fresh or dried herbs and spices.
- Add ice-cream or cream to some fruit or into a smoothie to increase kilojoules and nutrients.
- Try soft foods or clear liquids, which are easier to digest.
- Sip on juice, cordials, smoothies, soft drinks and sports drinks during the day to help keep you hydrated.
- Make meals as enjoyable as possible, e.g. play music, light candles or eat dinner with family or friends.
- Gentle physical activity can stimulate appetite. You could try taking a short walk around the block or some easy exercises.
- Speak to your doctor about trying some medicines that could help improve your appetite.
- See a dietitian for information about nutritional supplements, such as protein shakes, to ensure you don't lose too much weight.

## Breathlessness

People with advanced cancer often experience shortness of breath or breathlessness. This may sometimes be called dyspnoea.

Breathlessness can happen for many different reasons, including:

- fluid surrounding or in the lungs
- an infection
- the cancer itself
- scarring from radiation therapy
- pressure from a swollen abdomen
- anaemia (low red blood cell levels)
- underlying chronic breathing disorders, such as asthma or emphysema
- heart problems
- anxiety
- general weakness.

Symptoms of breathlessness include difficulty catching your breath, noisy breathing or very fast, shallow breaths. Although breathlessness can make you feel distressed and anxious, there are ways to prevent or reduce its impact on your quality of life.

Treatment will depend on the cause of the breathlessness. You may need to have any fluid around the lungs drained, or medicine prescribed to treat an infection or other lung problem. If breathlessness is caused by the lungs not supplying enough oxygen to your blood, your doctor may be able to arrange a portable oxygen cylinder.

Ask your doctor or nurse about medicines, such as a low dose of morphine, to manage the distress of breathlessness. See the opposite page for things you can do at home to help improve breathlessness.

## Ways to manage breathlessness



### Create a breeze

Use a handheld fan to direct a stream of air across your face if you feel short of breath. Or you could open and sit near a window to increase airflow.



### Lean on a pillow

Sit up or lean forward on a table with an arm crossed over a pillow to allow your breathing muscles to relax. You can also use a walking frame when out or lean on the shopping trolley at the supermarket, as this position can ease your breathing.



### Keep up your fluid intake

It's important to make sure you drink plenty of fluids throughout the day. Being dehydrated can make you feel more breathless.



### Take time to sit down

Spread out activities during the day or break them up into smaller tasks. Place chairs around the house so that you can sit down between activities or when moving from room to room.



### Try relaxation programs

Listen to a relaxation recording or learn ways to relax. Some people find breathing exercises, acupuncture and meditation helpful. Cancer Council has free relaxation and meditation recordings in the *Finding Calm During Cancer* podcast series.

## Key points about managing symptoms

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### **Sleeping problems and fatigue**

- Difficulty sleeping may be caused by cancer, treatment, pain, breathlessness, depression or anxiety. Treating it is important to keep up energy levels.
- Constant tiredness (fatigue) can be distressing. If you feel it is getting worse, tell your doctor. It may be caused by something that can be treated.

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### **Managing pain**

- Whether you experience pain will depend on the cancer. Pain can usually be controlled.
- Pain-relieving medicines (analgesics) can be mild, like paracetamol, moderate like codeine, or strong like morphine.
- Palliative care services are specifically trained in pain management. They can assess your needs to work out the most effective drug, the right dose and the best way to take it.
- It is better to treat the pain early, rather than wait to treat the pain when it builds up.
- Surgery, chemotherapy and radiation therapy can all be used to control pain.
- A nerve block can relieve pain if cancer is affecting the nerves, but this is usually short term.

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### **Other symptoms**

- Cancer treatments, cancer growth or the location of the cancer can make you feel sick (nauseated). This can usually be controlled with medicines. You may need surgery for organ blockages (e.g. in the bowel).
  - You may also experience a loss of appetite. Eat what you feel like when you feel like it, and relax any usual dietary restrictions.
  - If you have trouble breathing or breathlessness, let your doctor know, as this can be managed.
-



# Looking ahead

This chapter explains the practical, medical and legal issues to consider when you're told the cancer is advanced. Organising personal, financial and legal paperwork and making decisions about the future is hard. But planning ahead is important whether you have a serious illness or not.

Sorting out paperwork and getting your affairs in order can help you feel more in control of your life and what the future holds, bring a sense of relief, and allow you to focus on treatment and living.

## Dealing with bills and debts

There are many different types of costs that can add up during diagnosis and treatment. If you are concerned about money, this can add to the worry and stress of being diagnosed with advanced cancer.

Ask your doctor whether there are ways to reduce your treatment costs. They can also refer you to a social worker for advice. Depending on your circumstances, you may need to consider ways to manage the financial impact of advanced cancer.

## Making payment arrangements

If you are having difficulty paying your utility bills, such as electricity, gas, water, phone or internet, contact your provider. You may be able to access flexible payment arrangements, discounts, rebates or concessions through their hardship program. Check with the hospital social worker whether other options are available in your state or territory. You can contact the National Debt Helpline on 1800 007 007 or online at [ndh.org.au](http://ndh.org.au) for free financial counselling and advice.

## Organising your paperwork

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Keeping paperwork up to date and in one secure place will make it easier if someone needs to help you with money or legal matters. Discuss your legal arrangements with your family, and let them know how to contact your lawyer. If you have an advance care directive (see page 58), give a copy to your health care team so they know about any decisions you have made.

Documents to get together include:

- social media login and passwords
  - birth, marriage/divorce certificates
  - bank and credit card details and passwords
  - investment information (e.g. shares)
  - Centrelink and Medicare details
  - superannuation and insurance
  - house title/lease
  - loan details (e.g. house, car)
  - passport
  - will (see page 60)
  - documents appointing substitute decision-maker/power of attorney
  - advance care directive
  - funeral information (see page 61).
- 

## Accessing superannuation early

In Australia, you can access your superannuation (super) if you are 65 years old or if you have retired (depending on your age). You can also apply to access your super early in particular circumstances, including:

- on compassionate grounds, including to pay for medical treatment
- if you are facing severe financial hardship
- if you are diagnosed with a life-limiting illness – you may need to provide supporting documentation, which your doctor can arrange.

You can apply to access your super early through your super fund or the Australian Taxation Office (ATO). Visit [ato.gov.au](http://ato.gov.au) and type “early access to your super”, or you can also call them on 13 10 20.

Cancer Council may be able to connect you with a professional to help you access your super. Call 13 11 20 for more information.



Cancer Council's *Cancer and Your Finances* booklet has more detailed information. Fact sheets on superannuation, insurance, debts and funerals are also available in many states and territories. Call 13 11 20 for these free resources, or download copies from your local Cancer Council website.

## Check your insurance

People often don't realise that they may have insurance attached to their superannuation. Some super funds may offer insurance by default – so you may be covered as long as you didn't choose to opt out.

Types of insurance provided through super funds can include income protection, total and permanent disability, and life insurance (may be called death cover).

To find out whether you have insurance through your super or how accessing your super early will affect your insurance entitlements, talk to your super fund and insurer, or to a financial planner.

## Advance care planning

It can be 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 of discussing future care and preparing any necessary documents is called advance care planning. It ensures your family and health care team know and respect your treatment wishes if you can't make decisions for yourself (called losing decision-making capacity) or can't communicate your wishes for any reason. Planning ahead can give you peace of mind and help your family feel less anxious if they are asked to make important health decisions for you.



Aboriginal and Torres Strait Islander peoples can find culturally specific cancer information on your local Cancer Council website, or you can call Cancer Council 13 11 20.

Advance care planning can involve:

- talking and making decisions about what is important to you for quality of life
- discussing what treatments you may or may not want, including where you want to receive care (e.g. at home if possible)
- completing an advance care directive (see page 58)
- appointing a substitute decision-maker (see page 59).

Advance care planning may be confronting, but it doesn't mean that you have given up or will die soon. The process gives you the security to know that you have formalised plans for the future, and that you can now focus on treatment and living. You can also change an advance care directive at any time if you want or need to.

You can include details about what you want in your advance care planning documents (see pages 58–59). For example, religious, spiritual or cultural beliefs that may affect your health care decisions can be recorded.

Many advance care planning documents are only used if there comes a time when you can't make decisions for yourself. However, you will need to be able to make clear decisions (have capacity) to complete an advance care directive (see page 58), as this is a legal document.

To find out more, call 1300 208 582 or visit [advancecareplanning.org.au](http://advancecareplanning.org.au) or [end-of-life.qut.edu.au](http://end-of-life.qut.edu.au). You can also get independent legal advice. Call Cancer Council on 13 11 20 if you feel anxious about planning.

## Steps in advance care planning

### 1. Talk to others



Use one of the following guides to help you think about your preferences and discuss them with family and friends:

- Advance Care Planning Australia's conversation starters [advancecareplanning.org.au/understand-advance-care-planning/starting-the-conversation](https://advancecareplanning.org.au/understand-advance-care-planning/starting-the-conversation)
- Palliative Care Australia's discussion starter [palliativecare.org.au/campaign/discussion-starters](https://palliativecare.org.au/campaign/discussion-starters).

It may also be helpful to talk to your doctor about the kinds of choices that may need to be made in the future.

### 2. Record your treatment goals



Many hospitals have their own forms for you to use. If not, you can find information relevant to your state or territory at [advancecareplanning.org.au](https://advancecareplanning.org.au). Documents must include:

- names and contact details of your substitute decision-maker (see page 59)
- outline of treatments, care or services that you do or do not want
- a signature and date for both you and your witness.

### 3. Make copies



- Share copies of your advance care documents with your GP, oncologist, palliative care team, substitute decision-maker, hospital and family or friends.
- Ask your doctor or hospital to include the plan in your medical record.
- Save it online at [myhealthrecord.gov.au](https://myhealthrecord.gov.au).
- Review the documents regularly – yearly is a good idea – and update them whenever your wishes change.

## Preparing legal documents

If you have not already done so, now is the time to think about appointing a substitute decision-maker, preparing an advance care directive and making a will. For any of these documents to be legally binding, you need to have decision-making capacity at the time of making the document. In general, having capacity means you are able to understand the choices that are available and the consequences of your decisions, and that you can communicate these choices. For more information, talk to your doctor or a lawyer. Each state and territory has different laws about what having capacity officially means, making advance care directives and appointing substitute decision-makers.

## Making an advance care directive

This written record of your goals, values, treatment preferences, and instructions for any future medical care, is used by your doctors, family and carers if they need to make decisions on your behalf. This is a legally binding document which has different names depending on where you live. It may be called an Advance Care Directive, Advance Health Directive, Health Direction or an Advance Personal Plan (see the box on the opposite page). You can save or print the form specific for your state or territory from [advancecareplanning.org.au](http://advancecareplanning.org.au), or order a printed starter pack to be mailed to you.

You may need the help of your doctor or lawyer to complete the form and make sure it's signed, dated and witnessed. Some hospitals use their own forms. If your needs change, you can choose to revise or replace it. Ask your doctor or hospital to add your directive to your medical record. You can also save it online at [myhealthrecord.gov.au](http://myhealthrecord.gov.au).

For more information, call the National Advance Care Planning Advisory Service on 1300 208 582 or visit [advancecareplanning.org.au](http://advancecareplanning.org.au).

## Appointing a substitute decision-maker

While you have capacity, you can formally appoint a substitute decision-maker. This is someone who can make legal, financial and/or medical decisions for you in the future, if you do not have capacity to decide. Your substitute decision-maker should be someone you trust and who understands your values and what you want for any future care. They do not have to be a family member, and you can appoint more than one person if you want. Depending on where you live, different documents are required to appoint a substitute decision-maker.

### Documents used for advance care planning

| State/<br>territory | Name for advance<br>care directive | Name for substitute<br>decision-maker document                               |
|---------------------|------------------------------------|------------------------------------------------------------------------------|
| ACT                 | Health Direction                   | Enduring Power of Attorney                                                   |
| NSW                 | Advance Care Directive             | Enduring Power of Attorney,<br>Enduring Guardian                             |
| NT                  | Advance Personal Plan              | Advance Personal Plan                                                        |
| QLD                 | Advance Health<br>Directive        | Enduring Power of Attorney,<br>Advance Health Directive                      |
| SA                  | Advance Care Directive             | Advance Care Directive,<br>Enduring Power of Attorney                        |
| TAS                 | Advance Care Directive             | Enduring Power of Attorney,<br>Instrument Appointing an<br>Enduring Guardian |
| VIC                 | Advance Care Directive             | Enduring Power of Attorney,<br>Medical Treatment Decision Maker              |
| WA                  | Advance Health<br>Directive        | Enduring Power of Attorney,<br>Enduring Power of Guardianship                |

If you cannot make decisions for yourself (lose capacity), and do not have an advance care directive (see page 58) or an appointed substitute decision-maker (see page 59), the law in each state and territory outlines who may make medical treatment decisions for you.

This is usually someone close to you, such as your spouse or partner, family member or close friend. For more information about who may make treatment decisions for you, visit [end-of-life.qut.edu.au/treatment-decisions/adults/state-and-territory-laws](http://end-of-life.qut.edu.au/treatment-decisions/adults/state-and-territory-laws).

## **Making a will**

A will is a legal document that sets out what you want to happen to your assets after you die. These assets are called your estate and may include your house, land, car, bank accounts, jewellery, clothes, household goods or investments. A will can also record your wishes regarding guardianship plans for any children.

Making a will is not difficult but it needs to be prepared and written in the right way to be legally valid. A will should be reviewed and updated as circumstances change. It is best to ask a lawyer to advise you, or contact the Public Trustee in your state or territory.

Cancer Council may be able to connect you with a lawyer to help you prepare a will. For more information, call 13 11 20.

If you die without a will, you are said to die intestate. Your assets – such as your house, money and belongings – are distributed to family members according to a formula provided by law. Although any will can be challenged in court, having a valid will usually means that your assets will go to the people of your choice, avoids extra expenses, and simplifies the process for your family.

## Making a funeral plan

Having advanced cancer can mean thinking about things you might not have otherwise – like making a will or even how you would want your life to be celebrated. Some people may want to think about what they want for their funeral, while other people may not.

If you want to plan your funeral, you could discuss your wishes with your family and friends, lodge a plan with the funeral director of your choice or record your wishes in your will. The executor is the name for the person you appoint to carry out the wishes left in your will. They should follow the directions in your will, but they are not legally bound to do so.

You can personalise your funeral to suit your cultural or spiritual beliefs. You may have just a few simple requests for music you want played or poems you'd like read, or you may have lots of ideas for the full service. You can also choose not to have a funeral at all or to have a non-traditional event such as a celebration of life. If you change your mind, you can alter these arrangements at any time.

To prearrange or prepay a funeral, talk to a funeral director. You can download a pre-planning information form from Funerals Australia (formerly the Australian Funeral Directors Association) at [funeralsaustralia.org.au](http://funeralsaustralia.org.au). It's important to let your family know of any arrangements like this that you have made. Copies of a prepaid funeral contract should be given to members of your family or filed with your will.



Aboriginal and Torres Strait Islander peoples can find information about cancer, Sorry Business and passing into The Dreaming at [ourmobandcancer.gov.au/sorry-business](http://ourmobandcancer.gov.au/sorry-business).

## Voluntary assisted dying

Voluntary assisted dying (VAD) is when a person with an incurable, life-limiting condition or illness chooses to end their life with the assistance of a doctor or health practitioner – using specially prescribed medicines from a doctor. “Voluntary” means that it is the choice of the unwell person to end their life.

Voluntary assisted dying is only available to people who meet all the strict conditions and follow certain steps as required by the laws where they live. This usually includes being aged over 18; an Australian citizen or permanent resident; having decision-making capacity; and having a terminal illness causing intolerable suffering and likely to cause death within a set timeframe.

It’s essential to check the latest updates and know the law and rules around participating in VAD. Rules may change over time and can vary according to your state or territory.

As of August 2026, VAD is operating in all 6 Australian states and the ACT. In the Northern Territory, VAD laws have been passed and VAD is likely to begin in 2028.

For comprehensive and current information on VAD for your state or territory, visit Queensland University of Technology’s End of Life Law in Australia at [end-of-life.qut.edu.au/assisteddying](https://end-of-life.qut.edu.au/assisteddying).

## Key points about looking ahead

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### Financial issues

- If you are having trouble paying your utility bills or are struggling with other debts, talk to your service provider or lender about your situation.
- Contact Centrelink and discuss your situation and what benefits may be available to you.
- If cancer causes financial issues, you may consider accessing your superannuation or claiming on insurance policies that are attached to your superannuation account.

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### Advance care planning

- It's helpful to update all your important documents and to keep them in one place. This will make it easier if a family member has to help you with financial and legal matters.
- You may want to think about your preferences for future health care and discuss these with others.
- A substitute decision-maker is someone you appoint to make decisions on your behalf if you are no longer capable of doing so. See [advancecareplanning.org.au](http://advancecareplanning.org.au).
- An advance care directive is an official document that records your preferences for your future health care. You can ask your doctor or the hospital to place a copy of the directive on your medical record. You can also save it online at [myhealthrecord.gov.au](http://myhealthrecord.gov.au).

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### Making a will and funeral plan

- A will is a document setting out who you would like to receive your assets after you die.
- Planning your funeral may be difficult, but it is an opportunity to personalise the occasion.

# Support and information

The availability of services varies depending on where you live – some are free, others may have a cost. For more information, talk to the social worker at your treatment centre or call Cancer Council 13 11 20.

## Useful organisations

### Accommodation

Cancer Council  
13 11 20

If you travel a long way for treatment, you may be able to access accommodation facilities or other travel or accommodation support.

### Cancer information

Cancer Council  
13 11 20  
**See back cover for  
Cancer Council websites.**

Cancer Council produces easy-to-read booklets and fact sheets on many types of cancer, treatment options, and emotional and practical issues.

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

Information and insights for anyone affected by cancer; includes a series on advanced cancer.

Cancer Australia  
**[canceraustralia.gov.au](http://canceraustralia.gov.au)**

Information about cancer from the Australian Government cancer control agency.

American Cancer Society  
**[cancer.org](http://cancer.org)**

Information about cancer from the largest voluntary health organisation in the US.

Macmillan Cancer Support  
**[macmillan.org.uk](http://macmillan.org.uk)**

Information about cancer from the leading UK cancer charity.

## Carer services

|                                                                                                  |                                                                         |
|--------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------|
| Carer Gateway<br>1800 422 737<br><a href="http://carergateway.gov.au">carergateway.gov.au</a>    | Practical information and resources and counselling for carers.         |
| CarerHelp<br><a href="http://carerhelp.com.au">carerhelp.com.au</a>                              | Information for people caring for someone at end of life.               |
| Young Carers Network<br><a href="http://youngcarersnetwork.com.au">youngcarersnetwork.com.au</a> | Support for young people under 25 caring for a family member or friend. |

## Counselling and mentoring services

|                                                                                                                               |                                                                                                                                      |
|-------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------|
| 13 Yarn<br>13 92 76<br><a href="http://13yarn.org.au">13yarn.org.au</a>                                                       | 24-hour culturally safe space to yarn about worries with an Aboriginal or Torres Strait Islander Crisis Supporter.                   |
| Australian Centre for Grief and Bereavement<br><a href="http://grief.org.au">grief.org.au</a>                                 | Online telehealth counselling service for people experiencing grief.                                                                 |
| Australian Psychological Society<br><a href="http://psychology.org.au">psychology.org.au</a>                                  | Use the “Find a Psychologist” search to look for a practitioner in your area.                                                        |
| Beyond Blue<br>1300 22 4636<br><a href="http://beyondblue.org.au">beyondblue.org.au</a>                                       | 24-hour telephone counselling service; online and email counselling available 7 days a week.                                         |
| Cancer Council’s Cancer Connect<br>13 11 20                                                                                   | Connect with people affected by cancer online, by phone or in person.                                                                |
| Cancer Hub<br>1800 431 312<br><a href="http://cancerhub.org.au">cancerhub.org.au</a>                                          | Camp Quality, Canteen and Redkite provide Cancer Hub to help families (with children aged up to 25 years) access a range of support. |
| Lifeline<br>13 11 14<br><a href="http://lifeline.org.au">lifeline.org.au</a>                                                  | 24-hour telephone crisis support and suicide prevention service.                                                                     |
| Suicide Call Back Service<br>1300 659 467<br><a href="http://suicidecallbackservice.org.au">suicidecallbackservice.org.au</a> | 24-hour telephone and online counselling for people affected by suicide.                                                             |

## Equipment and aids

Australia's National Equipment Database  
[askned.com.au](http://askned.com.au)

Advice on a range of products and services to help with aspects of day-to-day living, including mobility, sleeping, eating and personal care.

## Financial assistance

Services Australia  
132 717  
[servicesaustralia.gov.au](http://servicesaustralia.gov.au)

Financial support for people with a long-term illness and for primary carers.

National Debt Helpline  
1800 007 007  
[ndh.org.au](http://ndh.org.au)

Help with debt problems and finding a financial counsellor from Financial Counselling Australia.

Pharmaceutical Benefits Scheme (PBS)  
[pbs.gov.au](http://pbs.gov.au)

Assistance with the cost of prescription medicines.

## Funerals

Funerals Australia  
(03) 9859 9966  
[funeralsaustralia.org.au](http://funeralsaustralia.org.au)

Information about planning a funeral. Use the "Find a Member" search to look for a funeral director in your area.

National Funeral Directors Association of Australia  
[nfda.com.au](http://nfda.com.au)

Search for a funeral director near you and find information about planning a funeral.

Funeral Celebrants Association Australia  
[funeralcelebrants.org.au](http://funeralcelebrants.org.au)

Directory for finding a funeral celebrant in your local area.

## Future planning

Advance Care Planning Australia  
1300 208 582  
[advancecareplanning.org.au](http://advancecareplanning.org.au)

Information about planning for your future health care, including advance care directives.

## Home help and home nursing

Talk to your palliative care team, GP and/or health fund about the services that may be available for you. Some local councils provide services in the home or in the community and these can be organised as part of your palliative care. Private services are also available.

My Aged Care  
1800 200 422  
[myagedcare.gov.au](http://myagedcare.gov.au)

Information about different types of aged care services and eligibility.

## Legal and financial information

Cancer Council  
13 11 20

Cancer Council may be able to refer you to professionals for advice on legal or financial issues. This service may vary by location.

End of Life Law in Australia QUT  
[end-of-life.qut.edu.au](http://end-of-life.qut.edu.au)

Information about the law on end-of-life decision-making in each state and territory.

## Palliative care

Palliative Care Australia  
[palliativecare.org.au](http://palliativecare.org.au)

Information and resources; can link you to your local palliative care office.

CareSearch  
[caresearch.com.au](http://caresearch.com.au)

Australian Government website with palliative care information and links to services for patients and families.

## Respite care

Healthdirect Australia  
[healthdirect.gov.au/respite-care](http://healthdirect.gov.au/respite-care)

Links to respite care at home, in a respite care centre or, in some cases, a hospital or palliative care unit.

## Support groups

Telephone support groups  
Cancer Council 13 11 20

Includes groups for people with advanced cancer, for carers, and for dealing with grief.

Cancer Council Online  
Community  
[cancercouncil.com.au/OC](http://cancercouncil.com.au/OC)

Online discussion forum to ask or answer questions, or write a blog about your experiences with cancer.

# Question checklist

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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.

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## Diagnosis

- What type of cancer do I have?
  - What stage is my cancer?
  - How far has the cancer spread? How fast is it growing?
  - What is my prognosis? Do I need to have any more tests? If so, what will the tests involve?
  - How long am I likely to live? What are the usual survival times for people with this type of cancer?
- 

## Treatment

- What treatment do you suggest and why? How often will I need to have it? Will it affect my quality of life?
  - Are there any other effective treatment options for me? If not, why not?
  - What is the treatment goal? To control the cancer, or to relieve symptoms?
  - Are there any clinical trials I can join?
  - Are there any complementary therapies that might help?
  - If I don't have treatment, what can I expect? Will it affect my quality of life?
- 

## Side effects

- What treatment do you suggest for any pain or discomfort?
  - Are there any symptoms I should look out for and tell someone about?
  - What are the risks and possible side effects of each treatment?
- 

## Palliative care

- What support options are available to me? Where can I get palliative care?
  - Can I call the palliative care team at any time?
  - Does the palliative care team inform my GP and other specialists about my care?
  - Do I have to pay for any palliative care services?
  - Can you help me talk to my family about what is happening?
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# Glossary

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## **advance care directive**

A written document that records preferences for future medical and personal care and/or appoints a substitute decision-maker to make decisions for you. Some apply immediately; others are intended to apply at a time in the future when you don't have the capacity to make medical treatment decisions. May be called an Advance Care Directive, Health Direction, Advance Health Directive or an Advance Personal Plan. Each state or territory has different documents with different functions and purposes.

## **advance care planning**

When a person thinks about their future health care and discusses their preferences 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, Advanced Care Plan or "living will".

## **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.

## **allied health professional**

A university-qualified professional who works with others in a health care team to support a person's medical care (e.g. psychologist, social worker, physiotherapist, dietitian, etc).

## **alternative therapy**

An unproven therapy that is used in place of conventional treatment, often in the hope that it will provide a cure.

## **anaesthetic**

A drug that stops a person feeling pain during a medical procedure. Local and regional anaesthetics numb part of the body;

a general anaesthetic causes a temporary loss of consciousness.

## **analgesic**

A medicine used to relieve pain.

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## **cachexia**

Loss of body weight and muscle mass, causing weakness.

## **capacity**

Having the ability to make decisions and understand the impact of them, and be able to think things through to make decisions.

## **carer**

A person providing unpaid care to someone who needs assistance because of a disease (e.g. cancer), disability, mental illness or ageing.

## **chemotherapy**

A cancer treatment that uses drugs to kill cancer cells or slow their growth. May be given alone or in combination with other treatments. Chemotherapy can also be used as a palliative treatment to reduce the size of the cancer and help lessen pain.

## **chronic disease**

An illness or disease that is long lasting.

## **complementary therapy**

A range of therapies used alongside conventional treatment to improve general health, wellbeing and quality of life. Helps people cope with cancer symptoms and treatment side effects.

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## **depression**

Very low mood and loss of interest in life, lasting for more than 2 weeks. It can cause physical and emotional changes.

## **dyspnoea**

The medical term for difficulty breathing. Also called breathlessness.

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**enduring power of attorney/guardianship**

The name given to the legal document that allows you to appoint someone you trust to act on your behalf if and when you become unable to make decisions for yourself. You decide what decisions they can make, which can include financial, property, lifestyle, personal care, medical and treatment decisions. Also called substitute decision-maker.

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**hospice**

See palliative care unit.

**hypercalcaemia**

Higher than normal levels of calcium in the blood.

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**immunotherapy**

Drugs that use the body's own immune system to fight cancer.

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**life-limiting illness**

An illness that is unlikely to be cured and will cause death at some stage in the future. A person with a life-limiting illness may live for weeks, months or years.

**lymphatic system**

A network of vessels, nodes and organs that removes excess fluid from tissues, absorbs fatty acids and transports fat, and produces immune cells. Includes the bone marrow, spleen, thymus and lymph nodes.

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**malignant**

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

**malnutrition**

The imbalance of energy, protein or other nutrients in the body, which can impact health and how the body responds to cancer treatment and recovery.

**metastasis (plural: metastases)**

Cancer that has spread from a primary cancer in another part of the body. Also called secondary or advanced cancer.

**morphine**

An opioid. A strong and effective pain reliever that is commonly used to treat people with cancer who have pain.

**multidisciplinary care**

A system where all members of the treatment team discuss a patient's physical and emotional needs, as well as any other factors affecting their care. The team meets to review cases and decide on treatments.

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**oncologist**

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

**osteoporosis**

Thinning and weakening of the bones that can lead to bone pain and fractures.

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**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. Also known as supportive care. It is not just for people who are about to die, although it does include end-of-life care.

**palliative care unit**

A place that provides comprehensive care for people with a life-limiting illness. This may include inpatient medical care, respite care and end-of-life care for people unable to be cared for at home, or who don't wish to die at home. It may also offer day care facilities and home visits. Sometimes called a hospice.

**palliative treatment**

Medical treatment for people with advanced cancer to help them manage pain and other physical and emotional symptoms. Treatment

may include radiation therapy, chemotherapy or other therapies. It is an important part of palliative care.

### **power of attorney**

See substitute decision-maker; enduring power of attorney/guardianship.

### **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 person's disease.

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### **quality of life**

Your comfort and satisfaction, based on how well your physical, emotional, spiritual, sexual, social and financial needs are met within the limitations of your health and personal circumstances.

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### **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.

### **recurrence**

The return of a disease after a period of improvement (remission). Also called relapse.

### **relapse**

See recurrence.

### **respite care**

Alternative care arrangements that allow the carer and person with cancer a short break from their usual arrangements. The care can be given in a range of settings.

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### **secondary cancer**

See metastasis.

### **second opinion**

Talking to another specialist to consider

other treatment options or to confirm a recommended course of treatment.

### **substitute decision-maker**

A person who makes decisions on your behalf if you become incapable of making them yourself. The documents to appoint this person may be called an enduring power of attorney, an enduring power of guardianship or appointment of medical treatment decision-maker.

### **supportive care**

Care and support that aim to improve the quality of life of people living with cancer, their family and carers. See palliative care.

### **systemic treatment**

Cancer drugs that spread throughout the whole body. Includes chemotherapy, hormone therapy, immunotherapy and targeted therapy.

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### **targeted therapy**

Drugs that target specific features of cancer cells to stop the cancer growing and spreading.

### **tumour**

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

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### **voluntary assisted dying (VAD)**

When a person with an incurable, life-limiting condition or illness chooses to end their own life with the assistance of a doctor or health practitioner – using medicines specially prescribed by a doctor.

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### **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)
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# 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 experienced health professionals 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 131 450.



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

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*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**

Produced in collaboration with:



**Palliative Care**  
Australia

## Visit your local Cancer Council website

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

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

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

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

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

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

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

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

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

*This booklet is funded through the generosity of the people of Australia.  
To support Cancer Council, call your local Cancer Council or visit your local website.*

