



Living with Advanced Cancer

A guide for people with cancer,
their families and friends

Practical
and support
information

For information & support, call

13 11 20



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First published January 2003. This edition December 2019.

© Cancer Council Australia 2019. ISBN 978 1 925651 71 3

Living with Advanced Cancer is reviewed approximately every three years. Check the publication date above to ensure this copy is up to date.

Editor: Jenny Mothoneos. Designer: Emma Johnson. Printer: SOS Print + Media Group.

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.

We thank the reviewers of this booklet: Prof Nicholas Glasgow, Head, Calvary Palliative and End of Life Care Research Institute, ACT; Kathryn Bennett, Nurse Practitioner, Eastern Palliative Care Association Inc., VIC; Dr Maria Ftanou, Head, Clinical Psychology, Peter MacCallum Cancer Centre, and Research Fellow, Melbourne School of Population and Global Health, The University of Melbourne, VIC; Erin Ireland, Legal Counsel, Cancer Council NSW; Nikki Johnston, Palliative Care Nurse Practitioner, Clare Holland House, Calvary Public Hospital Bruce, ACT; Judy Margolis, Consumer; Linda Nolte, Program Director, Advance Care Planning Australia; Kate Reed-Cox, Nurse Practitioner, National Clinical Advisor, Palliative Care Australia; Helena Rodi, Project Manager, Advance Care Planning Australia; Kaitlyn Thorne, Coordinator Cancer Support, 13 11 20, Cancer Council Queensland.

We would like to thank the health professionals, consumers and editorial teams who have worked on previous editions of this title. This booklet is funded through the generosity of the people of Australia.

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 book with them.

All care is taken to ensure that the information in this booklet is accurate at the time of publication. Please note that information on cancer 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 eight state and territory Cancer Councils, we provide a broad range of programs and services to help improve the quality of life of people living with cancer, their families and friends. Cancer Councils also invest heavily in research and prevention. To make a donation and help us beat cancer, visit cancer.org.au or call your local Cancer Council.



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About this booklet

This booklet is for people who have advanced cancer. This means the cancer has spread from the original (primary) site or has come back (recurred).

Health professionals use several different terms to describe cancer that has moved beyond early stages, including secondary, metastatic, stage 4 and advanced. Sometimes health professionals don't use a particular name. In this booklet, we use the term "advanced cancer". Regardless of the words used, it's frightening to hear that the cancer has spread or come back.

This booklet offers general information about advanced cancer: what it is, how it is treated, what might happen and what support is available. There is also information for the family and friends of people who have advanced cancer. You may find reading about advanced cancer distressing – read what seems useful now and leave the rest until you're ready.

How this booklet was developed

This information booklet was developed with help from a range of professionals and people affected by cancer.

If you or your family have any questions, 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).



**Cancer
Council**
13 11 20

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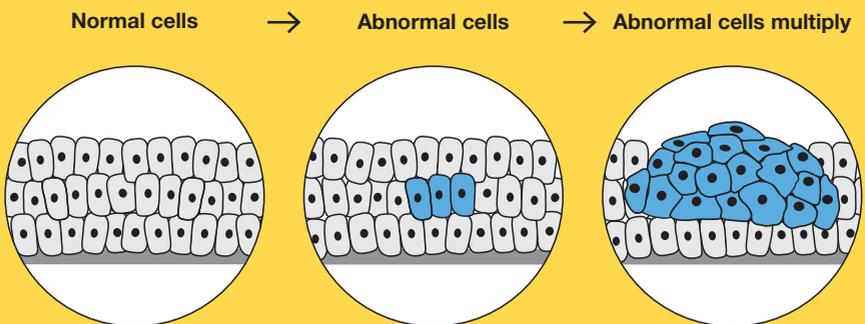


What is advanced cancer?

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 advance rapidly, and others behave unpredictably. Some types of cancer respond well to treatment, while other types are more difficult to treat.

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

How cancer starts

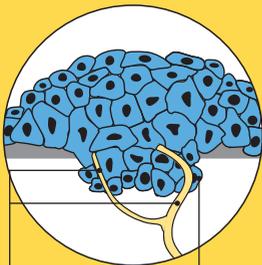


tumour at a new site. This is called a secondary cancer or metastasis. A cancer may spread to the lungs, brain, liver and bones. A metastasis keeps the name of the original cancer. For example, bowel cancer that has spread to the liver is still called metastatic bowel cancer, even though the main symptoms may be coming from the liver.

Although medical treatments may not be able to cure advanced cancer, they may be able to slow its growth or spread, sometimes for months or even years. Palliative care can also help manage cancer symptoms, which may include pain, and reduce side effects from cancer treatments. Other palliative care services can improve quality of life at any stage of advanced cancer.

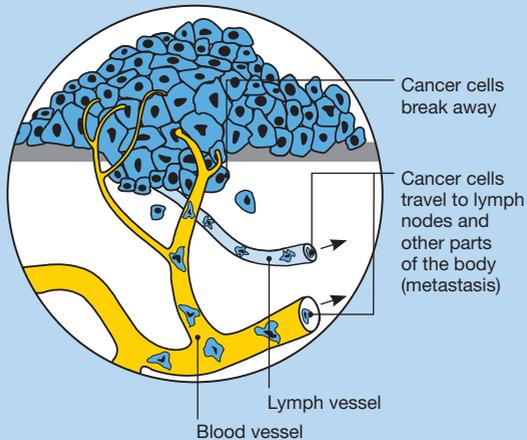
How cancer spreads

→ Malignant cancer



Grows own
blood vessels
(angiogenesis)

Invades
surrounding
tissue



Cancer cells
break away

Cancer cells
travel to lymph
nodes and
other parts of
the body
(metastasis)

Lymph vessel

Blood vessel



Key questions

Q: What happens now?

A: Some people's cancer may be advanced when they are first diagnosed. For others, the cancer may have spread or come back (recur) after treatment.

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

Q: What treatments are available?

A: Treatment will depend on where the cancer started, how far and where it has spread, and your general health, treatment goals and preferences for care.

Common treatments include chemotherapy, radiation therapy, surgery, targeted therapy, hormone therapy, and immunotherapy. These may be used alone or in combination. These treatments are often used as part of palliative treatment. Sometimes treatment is also available through clinical trials (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: Cancer and its treatment affect many aspects of a person's life. Depending on how you feel, you may be able to continue your usual routines, such as work, for some time. Or you may need to take time off or stop work altogether.

Emotional changes – You may experience emotional changes from the cancer and its treatment, for example, some hormone treatments affect people's emotions. Changes to your work, finances and health may also result in mood changes. See *Ways to manage your emotions*, pages 12–13.

Money concerns – Treatment or other services can be expensive, and costs can add up. This may mean you worry about taking time off from work or getting financial assistance. See *Dealing with bills and debts*, pages 54–55.

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

Practical issues – There can be practical issues you may have to think about to make life more comfortable, such as using medical equipment, modifying your home, or getting home help. If you need to travel a long distance from your home to the hospital, you may require transport or accommodation.

Q: Will palliative care help?

A: Palliative care is an approach that helps people with advanced cancer to live as fully and comfortably as possible. It's sometimes called supportive care. The main goal is to help you maintain your quality of life by identifying and dealing with your physical, emotional, cultural, social or spiritual needs. It involves a range of services offered by doctors, nurses and allied health professionals, such as physiotherapists, dietitians and psychologists, as well as volunteers and carers.

While some people delay or feel anxious about having palliative care because they believe it's only offered to people close to death, this type of care can improve quality of life from the time of diagnosis. It may be used occasionally or continuously for a few weeks or months. The number of people receiving palliative care for several years is increasing. It can help people who are referred early on in their diagnosis; there is no need to wait until the end of life. Palliative care also offers support to families and carers. For more information on palliative care, see pages 36–37.

Q: How long have I got?

A: After a diagnosis of advanced cancer, some people want to find out how long they have left to live, while others prefer not to know. It's a very personal decision.

If you would like to know the expected outcome (prognosis) of the cancer, you will need to talk to your doctor. This is a

difficult question for your doctor to answer and you may find their response is vague. As everyone is different, a doctor can give you an estimate based on what usually happens to people in your situation, but can't say exactly what will happen to you. The actual time could be longer or shorter.

Not all people with advanced cancer die from it – for some people, improved treatments can keep the disease under control for months or years. Other people find that different health issues become more serious than the cancer.

Some people find the uncertainty of having advanced cancer the most challenging aspect (see page 14). When faced with the possibility of dying, people often think about what they'd like to achieve in the time they have left. They may begin to live day by day, or take control of their life by completing practical tasks, such as preparing a will or advance care directive, or planning the funeral. For further details, see the *Planning ahead* chapter on pages 53–62.

- ▶ 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 or finding out the cancer has returned or spread can feel overwhelming. It is often hard to take in the news.

First reactions

When you are first told, or come to realise, that you have advanced cancer, you may feel a range of emotions.

If you didn't know you had cancer at all, a diagnosis of advanced cancer can sometimes feel like a double blow. If you've already been treated for cancer, you may experience different, possibly stronger reactions than when you heard for the first time that you had cancer. Sometimes you may even feel relieved – you may have suspected there was something wrong and now you know why.

There is no one way to react when you are told that the cancer is too advanced to cure. Everyone is different and will respond in their own way. Give yourself time to take in what is happening and do what is comfortable for you. Whatever you are feeling, it is likely those around you may be experiencing similar emotions.

Feelings you may experience

You may have a range of emotions, including:

Denial – A diagnosis of advanced cancer can be hard to accept. Some people deny the cancer can't be cured or that treatment options are limited. Denial can give you time to adjust to the news, but if it's ongoing it can also delay you from getting treatment or help.

Fear or anxiety – It is frightening to hear the cancer has come back, has spread or is at an advanced stage at diagnosis. Fear or anxiety (a feeling of worry or unease) may occur from the shock of diagnosis or having thoughts about dying.

Anger – You may feel angry because you've had to deal with cancer already, because you weren't diagnosed earlier, or because you feel your life has been shortened. Sometimes it may even be hard to work out exactly what your anger is about.

Guilt – It's common to blame yourself for the cancer, but the reason cancer spreads or doesn't respond to treatment is usually unknown. You may be worried about the impact cancer could have on your family or feel guilty that they may have to take care of you.

Uncertainty – You may feel you have less control over your life. It can be hard to adjust to an uncertain future, although some people may also feel a sense of hope in the uncertainty.

Loneliness – You may feel lonely at times even if you have people around you. It's natural to think nobody understands what you're going through. Your family and friends may have trouble dealing with the diagnosis and some may even distance themselves from you.

Sadness or depression – Feeling sad after a cancer diagnosis is common. If you have continued feelings of sadness, have trouble getting up in the morning or have lost motivation to do things that previously gave you pleasure, talk to your doctor – you may be experiencing depression.

Ways to manage your emotions

There are many simple things you can do to help you cope and feel more in control.



Join a support group

There are face-to-face, internet and telephone support groups where people meet regularly to share their experiences. See page 67 for more information about support groups.

Connect online

Use technology such as email, Facebook 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 to connect with others in a similar situation.



Find out what to expect

Information can help you understand what to expect, and plan for changes. This may make you feel more secure.



Accept help

Even when your friends are genuinely willing to help, it can sometimes be hard to ask. It may be useful to have one friend or relative to coordinate offers of help and to update others on your progress. Online tools can help organise volunteers, e.g. gathermycrew.org.au.

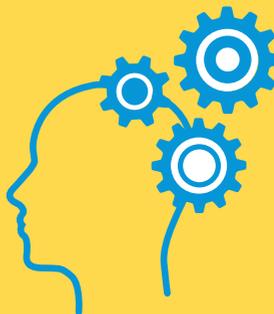


Try complementary therapies

Complementary therapies, such as relaxation, meditation and massage, may improve coping, decrease stress and anxiety, and improve your mood. See pages 38–39 for information.

Get help with how you're feeling

If at any stage you feel overwhelmed, speak to your doctor, as counselling or medicine – even for a short time – may help. Your GP may also refer you to a psychologist (see page 15). The organisation Beyond Blue has information about coping with depression and anxiety at beyondblue.org.au.



Find hope in other things

Focus on the small things that are still possible, e.g. having a coffee with a friend or watching the garden bloom.



Draw on spirituality

Some people find meaning and comfort in their religion, faith and spiritual beliefs. Others may experience spirituality more generally. A cancer diagnosis can challenge the beliefs of some people. It may help to talk about your feelings with a spiritual care practitioner, religious leader or counsellor.

Coping with advanced cancer

A diagnosis of advanced cancer often means finding new or different ways to cope with your emotions.

Managing uncertainty

Having advanced cancer often means living with uncertainty about what lies ahead. This can be challenging. Some people say they avoid thinking about what the future may hold by keeping busy or distracting themselves from their thoughts. While distraction can work in the short term, you may need to find your own way to manage difficult thoughts and emotions. Everyone will find their own way at their own pace. There is no right or wrong way.

🗨️ 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*

Loss and grief

A diagnosis of advanced cancer often involves a series of losses, such as the loss of good health, changing relationships, the loss of your hopes and future plans, or a loss of independence. You may need time to grieve for these losses.

Different people grieve in different ways. It is not as simple as going through stages. It is a process, and the intensity can vary. Some people describe different “waves” of grief, from mild to overwhelming. You may experience grief gradually and at different times – at diagnosis, if you start to feel unwell, or if treatment stops working.

A social worker or counsellor can help you and your family find strategies to manage the grief and loss you may experience. Your palliative care team can also provide grief support or refer you to someone who can help.

Being realistic

A common belief is that people with cancer need to stay positive. While you don't have to deny the reality that cancer is often frightening and serious, pressure to be optimistic all the time can drain your energy. It can also make it difficult to discuss any fears or sad feelings, which can make problems seem worse.

Try to be realistic about what is happening and talk to someone about how you're feeling. This may help you cope better and get the support you need.

You might find that talking to a counsellor or psychologist allows you to discuss your worries more openly. The Better Access initiative allows GPs to refer people to a psychologist for up to 10 free or subsidised sessions. Ask your GP for a referral to a psychologist or find your own at psychology.org.au/Find-a-Psychologist. Carers can also call the National Carer Counselling Program on 1800 242 636. This offers short-term counselling and is run by your local Carers Association.

Looking for meaning

Everyone has their own beliefs about the meaning of life. For some people, this might be found in spirituality or family; for others, it's found in nature or art. It's quite common for people diagnosed with advanced cancer to re-examine 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. While the diagnosis may cause some people to live life at a slower pace, others may feel an urgency to make the most of each day.

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

Celebrating your life

Having advanced cancer is often a chance for people to reflect on their life and all 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, 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.



Agnes's story

It was over 20 years ago 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 six 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.

Finding hope

When you've been told you have advanced cancer, you may find it hard to feel hopeful.

What you hope for may change with time. You may look forward to good days with understanding company or the love of family and friends. 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 aspect of their lives. Others find hope in small projects, such as completing a scrapbook of their life or planning a trip with their family.

“ 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*

While the cancer and its treatment can limit your activities, some people discover new strengths in themselves, and this gives them hope.

For some people, faith or spiritual beliefs can help them get through tough times. People who find hope in these beliefs describe feelings of optimism that are hard to explain to others. Cancer can also test people's beliefs. Either way, you may find it helpful to talk to a spiritual care practitioner, counsellor or psychologist for support.



The others in your life

It can be difficult to tell people you have advanced cancer. There is no easy way to share the diagnosis, but you may find it helps to practise what you are going to say.

How your family and friends react to your diagnosis will vary, and they may not react in the way you expect them to. They may need time to adjust to your diagnosis. They may also have similar fears and anxieties, and need as much information and advice, as you. Sometimes family members may feel more distressed than the person with cancer. This seems to be more common when there is a lack of communication between the person diagnosed with cancer and the people close to them.

You can guide your friends and family on how much you want to talk about the illness and the different issues you want to think about or plan together. Although you may want to protect the people you care about, sharing the news can often bring you closer.

Family and friends as carers

The people mentioned in this chapter may also care for you. They may not see themselves as a carer, rather that they are simply helping out as a natural part of their relationship with you. Some people willingly accept the extra responsibilities; others may feel pressured out of a sense

of duty. Caring for a person with advanced cancer can be challenging. The demands on your carers may increase as the cancer advances, and they will need support with emotional, practical and physical concerns.
▶ See our *Caring for Someone with Cancer* booklet.

The effect on people close to you

You may sometimes feel that the hardest part about having advanced cancer is the effect it will have on your family and friends.

Partners

The emotional support provided by a partner can affect how you cope with the diagnosis. How you talk with your partner about cancer depends partly on how you've always communicated. Many relationships can be challenged by a cancer diagnosis. This may be because of several factors, including an uncertain future, financial worries after the diagnosis, and feeling isolated.

Some studies suggest that partners have levels of distress similar to or greater than those of the person with cancer, and as a result partners may feel depressed and anxious. Being open and honest can help you and your partner through any anxieties, sadness and uncertainty, and your relationship may become stronger.

At times, you and your partner may not share each other's feelings, attitudes or opinions, and this can lead to tension. You may find it difficult if your partner doesn't want to talk about the diagnosis or your treatment options with you. They may unconsciously distance themselves as a way of coping or protecting you, without meaning to be hurtful.

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



In this booklet, the term “partner” means husband, wife, de facto, same-sex partner, boyfriend or girlfriend.

You could try telling your partner what you need most from them. Many people say that their biggest single need is for a sympathetic listener. Remind your partner that the important thing is not what they say but to be there and to listen. Let them know you are grateful for their support and that you understand it’s tough for them too.

Changes in sexuality and intimacy

We are all sexual beings, and intimacy adds to the quality of our lives. During the initial shock of diagnosis, sex might be the furthest thing from your mind. Over time, you may have questions about how cancer can affect your sexual and intimate life.

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 contact for fear of hurting you, or you may avoid physical contact for fear of rejection.

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 desired, you may find physical closeness in other ways, such as cuddling, stroking or massage. Talk with your partner about your feelings and concerns about the sexual changes in your relationship, and acknowledge the changes in intimacy.

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

Ways to manage other people's reactions

If roles become reversed	Talk about changes to avoid misunderstandings; discuss ways to meet each other's needs.
If your partner starts doing everything for you, and this affects your sense of independence	Explain that it's important for you to still feel involved at home and with the family, even if you can only do small tasks.
If everyone hides feelings to protect one another	Try to be open and honest and tell other people what you need most from them.
If others are overprotective or won't leave you alone	Set boundaries to maintain your sense of independence.
If they refuse to believe the prognosis	Give family and friends time to come to terms with the prognosis. Ask if they'd like to speak to your health care team.
If they avoid talking about the diagnosis because they think they may upset you	Guide others on how much you want to talk about the diagnosis and whether you're interested in discussing other topics.
If they ignore you or stay away	Make others feel more comfortable by letting them know you're interested in keeping in touch.

➤ Listen to our "Family Dynamics and Cancer" podcast episode.

How to tell children

There is no easy way to start this conversation, but it is important to let children know what is happening. It's natural to want to protect children, but they will often sense something has changed. If you've explained cancer and its treatment before, it might be easier to start the discussion. However, you might find it hard to talk about the cancer spreading and being difficult to treat.

The conversation may be easier if you think about the questions children may ask and work out a response beforehand. To help understand the diagnosis, children or grandchildren need age-appropriate explanations. These suggestions may help:

- Be honest and explain your prognosis using straightforward words.
 - 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 depending on their age, children may respond differently. This may range from displays of love and offers of help to withdrawal.
 - Discuss ways your children might be able to help you, while still managing their other commitments or responsibilities.
 - Organise or make time to spend with your children so you can create meaningful memories together.
- See our *Talking to Kids About Cancer* booklet.



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 networking sites, or write one letter and send copies to people. If you'd like to know what others are up to, ask for replies.

Friends

You may find your friends are invaluable in providing emotional and practical support. If you are not close to your family or if they don't live nearby, friends can be particularly helpful.

Some friends can listen to whatever you say – complaints, hopes, fears, wishes – without judging you, and without trying to cheer you up or giving advice. Others may avoid you or seem reluctant to talk about the diagnosis. These suggestions may help:

- 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 friends offer information you're not comfortable with (e.g. details of an alternative therapy used by a friend or celebrity who has had a surprising recovery), change the topic or let them know you are comfortable with the care provided by your treatment team.

When you don't want to talk

You may find that you don't want to talk about your fears and concerns with family and friends. This may be because you feel uncomfortable discussing private matters, you don't have the words to describe how you feel, or you fear becoming upset. Sometimes putting things into words makes it seem more real, and you may not feel ready to discuss some of these concerns.

Everyone handles a cancer diagnosis in their own way. If you don't want to talk, other people should respect your wishes.

Ways to share how you're feeling

If you are having trouble talking to others about personal issues, you can share the experience in the following ways:

Let others help – Try to allow friends and family to provide support, as this can help you adjust to your situation and cope better with your own emotions.

Join a support group – Talking about your fears and concerns with people who are going through a similar experience can often be easier. Join a support group, talk to a health professional or call Cancer Council 13 11 20.

Express your feelings creatively – Explore your feelings by writing in a journal, creating artwork or composing a song.



Making treatment decisions

Deciding whether to have treatment for advanced cancer can be difficult. 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. You may want to consider what quality of life means to you. Perhaps you would choose chemotherapy if it meant you could have two good weeks each month. Or you might value being able 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, the available treatments and possible side effects can help you weigh up the options and make a well-informed decision.

Record the details – When your doctor first tells you that you have advanced cancer, you may not remember everything you are told. Taking notes can help you or your might like to ask. It is a good idea to have a family member or friend go with you to appointments to join in the discussion, write notes or simply listen.

Ask questions – 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 to get a second opinion from another specialist to confirm or clarify your doctor's recommendations and reassure you that you have explored all of your options. Specialists are used to people doing this. Your GP or specialist

can refer you to another specialist and send your initial results to that person. You can get a second opinion even if you have started treatment or still want to be treated by your first doctor. You might decide you would prefer to be treated by the second specialist.

Talking about treatment decisions – Discussing the kind of care you might want in the future can be difficult. However, 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 for you. Palliative Care Australia has developed a discussion starter that can help you reflect on your preferences for care and talk about them with your family. See dyingtotalk.org.au/discussion-starter.

Should I join a clinical trial?

For some people with advanced cancer, taking part in a clinical trial may be a way to have new therapies. 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, clinical trials nurse or GP, 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.

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

When treatment seems too much

It can seem worthwhile dealing with treatment side effects for a primary cancer. But when a cure is unlikely, you may not want to have treatments that leave you feeling exhausted or sick, even if they may help you to live longer.

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

Refusal of medical treatment

You have the right to consent to, stop or refuse any treatment offered. If you stop or refuse treatment, your medical team must be confident that you understand the treatment proposed and the consequences of not having it. You can stop or refuse each treatment separately – 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, which your treating doctors must follow. You can appoint a substitute decision-maker to make treatment decisions if you are no longer able to do so. See pages 56–61.



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 months or years. If treatment is no longer controlling the cancer, the aim of treatment is to relieve the physical and emotional symptoms of cancer (palliative treatment).

New drugs are constantly becoming available, so if your current treatment stops working or you are finding it hard to cope with the side effects, ask your doctor about what else you can try. Also, ask if you are eligible to join 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 or injected into the bloodstream to reach cancer cells throughout the body. Examples include chemotherapy, immunotherapy and hormone therapy. Treatment that affects only a certain part of the body might also be used to relieve some symptoms. Examples include surgery and radiation therapy.

These treatments can also be used palliatively, which means they aim to manage the physical and emotional symptoms of cancer.

A range of health professionals who specialise in different aspects of care will work as a multidisciplinary team (MDT) to treat you. See the table on the next two pages.

- See our publications on chemotherapy, surgery, radiation therapy, immunotherapy, targeted therapy and palliative care.

Health professionals you may see

general practitioner (GP)	assists you with treatment decisions and works in partnership with your specialist in providing ongoing care
medical oncologist*	treats cancer with drug therapies such as chemotherapy, targeted therapy and immunotherapy (systemic treatment)
radiation oncologist*	treats cancer by prescribing and overseeing a course of radiation therapy
surgeon*	surgically removes tumours and performs some biopsies; specialist cancer surgeons are called surgical oncologists
haematologist*	diagnoses and treats diseases of the bone marrow, blood and lymphatic system; prescribes chemotherapy and other drug therapies
nurses	administer drugs and provide care, information and support throughout treatment; may be a community nurse, specialist palliative care nurse or a palliative care nurse practitioner
community nurse	visits you at home to supervise medical care, assesses your needs for supportive care, and liaises with your GP and MDT as required
cancer care coordinator	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)

palliative care team	specialise in pain and symptom control and psychological support to maximise wellbeing and improve quality of life
dietitian	recommends an eating plan to follow during and after treatment
pharmacist	dispenses medicines and gives advice about dosage and side effects
physiotherapist	helps with maintaining movement and mobility, and preventing further injury
occupational therapist	assists in adapting your living and working environment to help you resume usual activities after treatment
social worker	links you to support services and helps you with emotional, practical and financial issues
psychologist, clinical psychiatrist*	help you manage your emotional response to diagnosis and treatment
spiritual care practitioner	talks about spiritual matters and helps you reflect on your life and search for meaning; also known as spiritual care adviser, chaplain, pastoral carer

**Specialist doctor*

Chemotherapy

Chemotherapy is the most commonly used treatment when cancer has spread. The drugs kill cancer cells or slow their growth. There are many types of chemotherapy drugs, which 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.

Most chemotherapy drugs are given by injection or drip into a vein (intravenously), but some can also be taken as tablets or capsules (orally). Ask your doctor which combination of drugs is best for you, and how long your treatment will last.

Side effects – Some chemotherapy drugs cause tiredness, bowel changes, nausea and hair loss. Many of these 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 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, weight gain and sweating. Hormone therapy can also affect your fertility. It may bring on menopause in women. If you have been through menopause, hormone drugs called aromatase inhibitors may be used and these may cause thinning of the bones (osteoporosis) and vaginal dryness.

Targeted therapy

This is a type of drug treatment that attacks specific features of cancer cells, known as molecular targets, to stop the cancer growing and spreading. Targeted therapy drugs work in a different way from chemotherapy drugs. Chemotherapy drugs also circulate throughout the body, but they particularly affect cells that divide rapidly.

Targeted therapy drugs are used to control cancer growth. They 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.

The Pharmaceutical Benefits Scheme (PBS) subsidises the cost of some targeted therapy drugs for certain cancers. Therapies 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. Different types of immunotherapy work in different ways. Some of these new drugs work by permitting the immune system to bypass “checkpoints” set up by the cancer that block the immune system.

Checkpoint immunotherapy is currently available in Australia for some types of cancer. It has worked well for some people, but it does not help everyone. Even if immunotherapy is recommended, it is difficult to predict whether it will work. New immunotherapy drugs are being rapidly developed – talk to your doctor about whether any are suitable for you.

Side effects – The side effects of immunotherapy drugs are different from those caused by chemotherapy. 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).

“ I was told that this new immunotherapy treatment was having great success with metastatic melanoma. The oncologist explained that there could be side effects. After the third infusion, I woke up with my heart going all over the place. The drug had drained my thyroid completely and I had to be cardio-averted to get the heart back to sinus rhythm. ” Annabelle

Surgery

Surgery can be used to:

- remove tumours from affected areas, such as the bowel or lymph nodes
- relieve discomfort caused by tumours that stop organs working properly or 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 injure them so they cannot grow, multiply or spread. Radiation therapy can be precisely targeted at cancer sites in your body. Treatment is carefully planned to have the greatest effect on the cancer cells and to limit damage to the surrounding healthy body tissues.

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

Side effects – Common side effects from radiation therapy include fatigue, skin problems and loss of appetite. These may be temporary or longer lasting.

How palliative treatment can help

Medical treatment is a key part of palliative care. Some examples of palliative medical treatment include:

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

Palliative care

Palliative care is person-centred care that helps people with a progressive life-limiting illness to live as fully and comfortable as possible. The main goal is to help you maintain your quality of life by identifying and meeting your physical, emotional, cultural, social and spiritual needs. It also provides support to families and carers.

Many people are reluctant to use palliative care because they think it is just for people who are dying, but it is useful at all stages of advanced cancer. Starting palliative care from the time of diagnosis can help improve quality of life.

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.

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

- 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.

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

For more information about what palliative care is and how it helps, visit the Palliative Care Australia website, palliativecare.org.au. Use the directory on this website to find a palliative care service in your local area, or speak to your doctor or nurse.

“ I’ve been having palliative treatment for five years. I’m not trying to get rid of the disease, just keeping it under control. My quality of life is excellent. ” *Kate*

Rehabilitation

Sometimes cancer can limit your activities. Rehabilitation is a way of improving your quality of life between or after treatments. It may help restore physical functioning 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, you may need something to do that helps you feel involved in life and connected with people. For most people, rehabilitation is organised through their treatment centre. If you have been treated in a private hospital, ask your doctor about the availability of 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.

Complementary and alternative therapies

You may wonder whether there are any complementary therapies you could try. There are many reasons people with advanced cancer consider using complementary therapies. You may want help managing the symptoms and side effects of conventional cancer treatment, such as fatigue, nausea or pain. Some people use complementary therapies to help them feel better and to feel they've got some control over their treatment.

Complementary therapies

Complementary therapies can be used together with conventional medicine, such as chemotherapy or radiation therapy.

Research has shown that some complementary therapies can 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
- **stress** – meditation, relaxation, counselling, support groups, spiritual practices
- **nausea and vomiting** – acupuncture, hypnotherapy.

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

➤ See our *Understanding Complementary Therapies* booklet.



Let your doctor 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.

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 be effective.

When cancer has spread and treatment options are limited, some people consider alternative therapies. Friends and family may also tell you about 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 also be expensive and could affect management of your symptoms.

Be suspicious if any treatment:

- claims to cure all cancers
- requires you to travel overseas
- claims the medical/pharmaceutical industry wants to stop its use
- claims to have 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 spot and avoid scams. To find out more, visit scamwatch.gov.au.



Key points about treating advanced cancer

Treatment goal Treatment aims to control the cancer, slow down its spread and manage any symptoms.

Treatment options There are different types of treatment for advanced cancer that may be used separately or in combination.

- Common treatments**
- Chemotherapy is the most commonly used treatment when cancer has spread.
 - Surgery can be used to remove tumours that might be causing pain.
 - 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.
 - Hormone therapy is used for cancer that grows in response to hormones. It can slow tumour growth.
 - Palliative care helps you manage the symptoms of cancer or its treatment, and can help maintain your quality of life.
 - Contacting a palliative care team early in your illness means that you can find out what may help now and in the future.
 - Rehabilitation is another way of improving your quality of life during or after treatment.
 - Some complementary therapies can help reduce side effects. Cancer Council does not support the use of alternative therapies.



Managing symptoms

People may experience many different symptoms when they have advanced cancer. Common symptoms include pain, nausea, loss of appetite, breathlessness and tiredness. While it may not be possible to control all symptoms, the suggestions in this chapter can help make you as comfortable as possible. As the disease progresses, the intensity of symptoms and how often you experience them will vary, and this may affect what you are able to do.

The relief of symptoms is one of the aims of the palliative care team. Contact them to work out what help you need.

Pain

Many people with advanced cancer worry they will be in pain, but not everyone will have 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 doctors and nurses are specifically trained in pain management.

There are many ways to relieve pain, including:

- pain medicines (see opposite page)
- pain-relieving procedures for nerve pain (see page 44)
- complementary therapies such as massage, meditation, relaxation, acupuncture or hypnotherapy (see pages 38–39)
- chemotherapy, radiation therapy or surgery (see page 44).

Everyone experiences pain differently, so it may take time to find the most effective pain relief or combination of treatments for you. Using tools, such as a pain scale or pain diary, can help you describe your pain and how it is affecting you. This will help your pain specialists 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 help keep the pain under control. It's better to take medicine regularly, rather than waiting for the pain to build up. This is called staying on top of the pain. Controlling the pain may allow you to continue with activities you enjoy for some time and offer a better quality of life.

Pain medicines

Medicines that relieve pain are called analgesics (also known as pain relievers, painkillers and pain medicines). Depending on the type of pain 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.

Some people worry about becoming addicted to pain medicine, but this is unlikely when medicines are taken palliatively. Your health care team will monitor you to avoid potential side effects. Any side effects, such as constipation or drowsiness, can usually be managed.

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

Other ways to control pain

You may also be given other types of medicine to take with the main pain medicine. These could include 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 you have. Delivering the pain medicine directly into the nerves in the spine via a tube (epidural) usually provides short-term relief. If longer-term pain control is needed, the epidural can be connected to a pump.

Cancer treatments for pain relief

Chemotherapy, radiation therapy and surgery may also be used to control pain.

Chemotherapy – Uses drugs to shrink a tumour that is causing pain because of its size or location. It can also slow the growth of the cancer and help control symptoms, including pain, loss of appetite and weight loss.

Radiation therapy – Uses radiation, such as x-rays, to shrink a tumour and reduce

discomfort. For example, it may relieve headaches by shrinking cancer that has spread to the brain from another part of the body. Often a single treatment can be used.

Surgery – An operation can remove a single tumour in the soft organs; treat a bowel obstruction that is causing pain; or improve outcomes from chemotherapy and radiation therapy by reducing the size of a tumour.

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 of the bowel or the location of the cancer. Nausea can usually be managed with medicines. See the next 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're going past the place where you were treated.

Blockage in the bowel – Sometimes cancer in the abdominal area 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.

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 help but 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.

Ways to manage symptoms of advanced cancer

Nausea and vomiting

- Eat small meals or snacks 5–6 times during the day. 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 food or drink with ginger, e.g. ginger ale, ginger tea or ginger biscuits.
- Take anti-nausea medicines as prescribed. Let the doctor know if the medicines don't seem to be working.
- Avoid fried, greasy or spicy foods or those that have strong smells.
- Use stress-reduction techniques, such as meditation.

Loss of appetite

- Focus on eating foods you enjoy.
- Eat what you feel like, when you feel like it, e.g. have 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. During treatment, maintaining your weight is more important than avoiding full-fat foods.
- Add flavour to foods with lemon juice, herbs and spices.
- Add ice-cream or cream to fruit or a smoothie to increase kilojoules and nutrients.
- Sip on juice, cordials, soft drinks and sports drinks during the day to keep hydrated.
- Make meals as enjoyable as possible, e.g. play music, light candles or eat with friends.
- Gentle physical activity can stimulate appetite, e.g. take a short walk around the block.
- Soft food and clear liquids may be easier to digest.



Breathlessness

- Use a handheld fan or open a window to increase airflow near your face.
- Sit up or lean forward on a table with an arm crossed over a pillow to allow your breathing muscles to relax.
- Wear loose-fitting clothing around your waist and chest.
- Drink plenty of fluids. Being dehydrated can increase breathlessness.
- Place chairs around the house so that you can sit down between activities or when moving from room to room.
- Try to relax or practise different breathing techniques.
- Use a walking frame or lean on the shopping trolley when at the supermarket, as the position or pace can ease your breathing.
- Spread out activities during the day or break them up into smaller tasks.

Fatigue

- Plan activities for the time of day when you feel less tired, and include rest times.
- Do regular gentle activities, such as 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 our relaxation and meditation recordings.
- Have several short naps rather than one long rest during the day.
- Limit visitors if you find they are tiring you.
- Limit the amount of alcohol you drink. Alcohol can cause tiredness and energy loss.
- Use Meals on Wheels or other home delivery meal companies that bring prepared food to you, or buy frozen meals from the supermarket.

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.

A loss of appetite often leads to weight loss and malnutrition. Eating is important to help you maintain your strength, function and quality of life. However, it's not necessary to force yourself to eat; this may only make you feel uncomfortable and cause vomiting and stomach pain. See page 46 for ways to manage loss of 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 from your doctor or dietitian to buy them.

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

› See our *Nutrition and 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

Shortness of breath

People with advanced cancer often experience shortness of breath (breathlessness). This is also called dyspnoea.

Breathlessness can occur for different reasons, including:

- fluid surrounding the lungs
- 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 caused by chemotherapy.

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 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 can arrange a portable oxygen cylinder.

See page 47 for things you can do to improve breathlessness. Ask your doctor or nurse about medicines, such as a low dose of morphine, to manage feelings of distress.

Fatigue

For many people, extreme or constant tiredness (fatigue) can be a major problem, particularly as the cancer advances. You may find feeling fatigued distressing and frustrating. Some people say the fatigue is worse than any pain or nausea they've experienced.

Fatigue can be caused by a range of things, such as:

- anxiety or depression
- poor sleep
- infection
- progression of the cancer
- anaemia (low red blood cell levels)
- cancer treatment such as chemotherapy or radiation therapy
- loss of weight and muscle tone
- drugs such as analgesics, antidepressants and sedatives.

Tell the doctor or nurse if you think you are becoming weaker or more fatigued. If anaemia is making the fatigue worse, it can be managed. You may be referred to an occupational therapist who can teach you ways to save your energy.

- See page 47 for some things you can do to manage fatigue, and our *Fatigue and Cancer* fact sheet.

“ 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

Sleeping problems

Getting enough sleep is important for maintaining your energy levels, reducing fatigue and improving 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 what might be helpful for you. Your medicines may need adjusting or sleep medicines may be an option.



Ways to improve sleep

- Try to do some gentle physical activity every day. This will help you sleep better. Talk to a physiotherapist or exercise physiologist, who can tailor an exercise program, and an occupational therapist, who can suggest equipment to help you move safely.
- Limit or avoid smoking, drinking alcohol and caffeine, and eating spicy food.
- Avoid using technology, such as a television, computer or smartphone, before bed as the blue light tells your body it's time to wake up.
- Follow a regular routine before bed and set up a calm sleeping environment.
- Keep the room dark, quiet and at a comfortable temperature.
- Use relaxation practices, such as listening to gentle music, a recording of rain sounds or Cancer Council's relaxation recording, 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.



Key points about managing symptoms

Pain

- Whether you experience pain will depend on the size and location of 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 than wait to treat the pain when it builds up.
- Chemotherapy, radiation therapy and surgery 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.

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 also experience a loss of appetite. Eat what you feel like when you feel like it, and relax dietary restrictions.
- If you have trouble breathing or breathlessness, let your doctor know, as there may be treatments that help.
- Constant tiredness can be distressing. If you feel it is getting worse, tell your doctor. It may be caused by something that can be treated.



Planning ahead

This chapter explains the practical, medical and legal issues to consider when you're told the cancer is advanced.

Finding all your personal, financial and legal paperwork and deciding what to do can be difficult. However, planning ahead is important whether you have a serious illness or not. 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.

Organising your paperwork

It's helpful to have all of your paperwork up to date and in one secure place. This will make it easier if a family member or friend has to help you with financial and legal matters.

Important documents to get together might include:

- birth, marriage or divorce certificates
- bank and credit card information, passwords
- investment details (e.g. shares, funds)
- Centrelink and Medicare details
- superannuation and insurance information
- house title/lease documents
- loan details (e.g. house, car)
- passport
- will (see page 58)
- document appointing a substitute decision-maker (see page 59)
- advance care directive (see page 59)
- funeral information (see page 61).

Discuss your legal arrangements with your family, and let someone know how to contact your lawyer.

Dealing with bills and debts

There are many different types of costs that can add up during diagnosis and treatment. If you are struggling financially, 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 for free financial counselling and advice.



This is only an introduction to these issues. 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 digital versions from your local Cancer Council website.

Accessing superannuation early

In Australia, you need to be at least 55 years old and retired before you are allowed to access your superannuation (super). However, you can apply to access your super early under particular circumstances:

- on compassionate grounds to pay for medical treatment
- if you're facing severe financial hardship
- if you're diagnosed with a terminal illness – you may need to provide supporting documentation.

To access your super early, contact the Australian Taxation Office (ATO). Visit ato.gov.au and type “early access to your super”. You can also call the ATO on 13 10 20, or contact your super fund.

Cancer Council's Legal and Financial Referral Service may be able to connect you with a professional who can help. Call 13 11 20 for more information.

Check your insurance

People often don't realise that they may have insurance attached to their super. Many industry super funds, as well as some retail funds, offer insurance by default. In many cases, you will be covered as long as you did not 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 is called advance care planning, and it helps ensure that your family and health care team will make decisions that respect your treatment preferences when you are unable to communicate your wishes. Advance care planning involves:

- appointing a substitute decision-maker (see page 59)
- completing an advance care directive (see page 59).

Your advance care documents can be as simple or as detailed as you like. If you have religious, spiritual or cultural beliefs that may affect your health care decisions, you can record these in your advance care documents. You need to be an adult and have capacity (see page 58) to complete advance care documents.

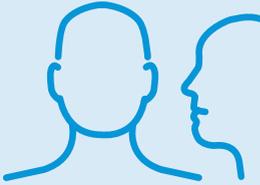
Advance care planning doesn't mean that you have given up or will die soon – it gives you the security to know that you have planned for the worst and that you can now focus on treatment and living. It only comes into effect if you are unable to make decisions for yourself.

Studies show that families of people who have done advance care planning feel less anxiety and stress when asked to make important health decisions for other people.

Each state or territory has different laws about advance care directives and substitute decision-makers. To find out more, visit advancecareplanning.org.au or call 1300 208 582. You can also seek independent legal advice.

Steps in advance care planning

1.



Talk to others

Use one of the following guides to reflect on your preferences and discuss your choices with family and friends:

- Advance Care Planning Australia's conversation starters – advancecareplanning.org.au/individuals/how-to-start-the-conversation
- Palliative Care Australia's discussion starter – dyingtotalk.org.au/discussion-starter.

2.



Record your treatment goals

For information relevant to your state or territory, visit advancecareplanning.org.au. Documents must include the following details:

- 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
- 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.
- Review the documents regularly and update them whenever your wishes change.

Preparing legal documents

If you have not already done so, now is the time to think about making a will, appointing a substitute decision-maker, and preparing an advance care directive.

For any of these documents to be legally binding, you need to have capacity at the time of signing the document. Having capacity means you are able to understand the choices that are available and the consequences of your decisions, and are able to communicate your choices. For more information, talk to your doctor and lawyer.

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 help you or contact the Public Trustee in your state or territory. For more information, call Cancer Council's Legal Referral Service on 13 11 20.

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

Appointing a substitute decision-maker

You can appoint someone to make medical decisions for you if in the future you lose capacity to make these decisions yourself. These can include decisions about your medical care and treatment. This person is called a substitute decision-maker. They should be someone you trust and who understands your values and wishes for future care.

Depending on where you live, the documents for appointing this person may be known as an enduring power of attorney, enduring power of guardianship, or appointment of a medical treatment decision maker. See table on the next page for more information.

Making an advance care directive

A written record of your goals and instructions for future medical care is called an advance care directive. Depending on where you live, the document may also be known as an advance health directive or advance personal plan. Download the forms from advancecareplanning.org.au. You may need the help of your doctor or family to complete the form and ensure it is signed, dated and witnessed.

Generally, these documents are legally binding and should inform your doctors, family and carers if they need to make medical decisions for you. If your needs change, you can choose to revise or replace your advance care directive. Ask your doctor or hospital to place your directive on your medical record. You can also save it online at myhealthrecord.gov.au. For more information, see advancecareplanning.org.au. You can also read Cancer Council's *Getting your affairs in order* fact sheet – call 13 11 20 or visit your local Cancer Council website.

Documents used for advance cancer planning

State/ territory	Name for advance care directive	Name for substitute decision-maker
ACT	health direction	enduring power of attorney
NSW	advance care directive	enduring guardian
NT	advance personal plan	decision-maker
QLD	advance health directive	enduring power of attorney
SA	advance care directive	substitute decision-maker
TAS	advance care directive	enduring guardian
VIC	advance care directive	medical treatment decision maker
WA	advance health directive	enduring guardian

Voluntary assisted dying

Recent changes in Victoria mean that voluntary assisted dying for people who meet strict criteria is legal in Victoria. For more information, visit health.vic.gov.au and search for “voluntary assisted dying”.

Although the laws in some other states and territories are under review, euthanasia and voluntary assisted dying are not part of palliative care. To find out more, visit end-of-life.qut.edu.au for updates.

Palliative care and end-of-life services are widely available in Australia. These services can help maintain comfort and quality of life throughout advanced cancer.

› See our *Understanding Palliative Care* booklet.

Making a funeral plan

Some people may want to plan their own funeral, others 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 should follow the directions in your will, but is not 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 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 the Australian Funeral Directors Association at afda.org.au or Funeral Directors Australia at funeraldirectorsaustralia.com.au. It's important to let your family know of any arrangements you have made. Copies of a prepaid funeral contract should be provided to members of your family or filed with your will.



Key points about planning ahead

- 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.
 - If cancer causes financial issues, you may consider accessing your superannuation or claiming on insurance policies that are attached to your superannuation account.

- 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 will is a document setting out whom you would like to receive your assets after you die.
 - A substitute decision-maker is someone you appoint to make treatment decisions for you should you become unable to do so yourself. See advancecareplanning.org.au.
 - An advance care directive 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.

Making a funeral plan

Planning your funeral may be difficult, but is an opportunity to personalise the occasion.



Support and information

Help and support can help make life easier. The availability of services may vary depending on where you live. Some services are free, but others may have a cost. Talk to the social worker at the treatment centre or call Cancer Council 13 11 20 to find out what services are available.

Useful organisations

Accommodation

Patient Travel Assistance Schemes

wiki.cancer.org.au/policy/Patient_travel_assistance_schemes

Cancer patients and carers who travel a long way for treatment can often get shared accommodation, and the cost is sometimes subsidised.

Cancer information

Cancer Council 13 11 20

See back cover for local Cancer Council websites.

Cancer Council produces easy-to-read booklets and fact sheets on more than 25 types of cancer, treatment options, and emotional and practical issues.

Cancer Australia canceraustralia.gov.au

Information about cancer from the Australian Government cancer control agency.

American Cancer Society cancer.org

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

Macmillan Cancer Support macmillan.org.uk

Information about cancer from the leading UK cancer charity.

Cancer Council podcast cancercouncil.com.au/podcasts

Information and insights for anyone affected by cancer. Separate series on advanced cancer.

Carer services

CarerHelp carerhelp.com.au	Information for people caring for someone at end of life.
Carer Gateway 1800 422 737 carergateway.gov.au	Practical information and resources for carers.
Carers Australia 1800 242 636 carersaustralia.com.au	National body working with state and territory Carers Associations to provide information and counselling for carers.
National Carer Counselling Program 1800 242 636	Offers short-term counselling for carers. This service is run by your local Carers Association.
Young Carers youngcarersnetwork.net.au	Support for young people under 25 caring for a family member or friend.

Counselling and mentoring services

Australian Centre for Grief and Bereavement grief.org.au	Online telehealth counselling service for people experiencing grief.
Australian Psychological Society psychology.org.au	Use the “Find a Psychologist” search to look for a practitioner in your area.
Better Access initiative health.gov.au/mentalhealth-betteraccess	Medicare-subsidised referral to counselling through your GP.
Beyond Blue 1300 22 4636 beyondblue.org.au	24-hour telephone counselling service; online and email counselling available seven days a week.
Cancer Council's Peer Support Programs 13 11 20	Community of people affected by cancer that you can connect with online, by phone or in person.

Counselling and mentoring services (continued)

Camp Quality 1300 662 267 campquality.org.au	Programs and services for young people aged 0–13.
Canteen 1800 835 932 canteen.org.au	Online, phone and face-to-face counselling for people aged 12–25.
Lifeline 13 11 14 lifeline.org.au	24-hour telephone crisis support and suicide prevention service.
Suicide Call Back Service 1300 659 467 suicidecallbackservice.org.au	24-hour telephone and online counselling for people affected by suicide.
Equipment and aids	
Independent Living Centres Australia 1300 885 886 ilcaustralia.org.au	Advice on a range of products and services to help with aspects of day-to-day living, including mobility, sleeping, eating and transport.
Financial assistance	
Cancer Council's Legal and Financial Referral Service 13 11 20	Referral service for people affected by cancer facing legal or financial issues; free for eligible clients.
Centrelink 132 717 humanservices.gov.au	Financial support for people with a long-term illness and for primary carers.
National Debt Helpline 1800 007 007 ndh.org.au	Help with debt problems and finding a financial counsellor from Financial Counselling Australia.
Pharmaceutical Benefits Scheme (PBS) pbs.gov.au	Assistance with the cost of prescription medicines.

Funerals

**Australian Funeral
Directors Association**
1300 888 188
afda.org.au

Listing of funeral directors and information about planning a funeral.

Funeral Directors Australia
funeraldirectorsaustralia.com.au

Listing of independent funeral directors and information about planning a funeral.

**Funeral Celebrants Association
Australia**
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

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

Home help

Talk to your palliative care team, GP and/or health fund.

Some local councils provide services in the home or in the community.

My Aged Care
1800 200 422
myagedcare.gov.au

Information about different types of aged care services and eligibility.

Home nursing

Ask your local council or your palliative care team.

Can be organised as part of your palliative care. Private services are also available.

Legal and financial information

**Cancer Council's Legal and
Financial Referral Service**
13 11 20

Referral service for people affected by cancer needing help with legal or financial issues; free for eligible clients.

Palliative care

Palliative Care Australia
palliativecare.org.au

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

CareSearch
caresearch.com.au

Australian Government website that provides palliative care information and links to services for patients and families, as well as resources for health professionals.

Respite care

Carer Gateway
1800 422 737
carergateway.gov.au

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

Spiritual or pastoral care

Many hospitals have a spiritual care practitioner (pastoral carer). Ask your treatment team how to contact them.

Support groups

Face-to-face groups
Call Cancer Council **13 11 20** for details of local support groups.

Meet with others who understand what it's like to have cancer.

Telephone support groups
Cancer Council **13 11 20**

Includes groups for people with advanced cancer, for carers, and for the bereaved.

Cancer Council Online Community
cancercouncil.com.au/OC

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



Question checklist

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

Diagnosis

- What type of cancer do I have?
- How far has the cancer spread? How fast is it growing?
- What is my prognosis? How long am I likely to live?

Treatment

- What treatment do you recommend and why?
- Are there other treatment choices for me? If not, why not?
- Are there any clinical trials I can join?
- Are there any complementary therapies that might help?

Side effects

- What treatment do you suggest for any pain or discomfort?
- What are the risks and possible side effects of each treatment?
- What will happen if I don't have treatment?

Palliative care

- Can I have 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?



Visit the Palliative Care Australia website for more suggested questions at palliativecare.org.au/asking-questions.



Glossary

advance care directive

A written document intended to apply to a point in the future when you don't have the capacity to make medical treatment decisions. It provides a legal means for a competent adult to appoint a substitute decision-maker and/or record their preferences for future medical and personal care. May be called a health direction, an advance health directive or an advance personal plan.

advance care planning

When a person thinks about their future health care and discusses their values, beliefs and preferences with their family, friends and health care team.

advanced cancer

Cancer that is unlikely to be cured. The cancer may have spread to other parts of the body (secondary or metastatic cancer). Treatment can often control the cancer and manage symptoms.

allied health professional

A tertiary-trained professional who works with others in a health care team to support a person's medical care. Examples include psychologists, social workers, occupational therapists, physiotherapists and dietitians.

alternative therapy

A 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.

cachexia

Loss of body weight and muscle mass, and weakness.

capacity

Having the ability to make decisions and understand the impact of those decisions.

carer

A person providing unpaid care to someone who needs this assistance because of a disease such as cancer.

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.

chronic disease

An illness or disease that is long lasting.

complementary therapy

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

depression

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

dyspnoea

The medical term for difficulty breathing. Also called breathlessness.

enduring power of attorney/enduring power of guardianship

See substitute decision-maker.

hospice

See palliative care unit.

hypercalcaemia

Higher than normal levels of calcium in the blood.

immunotherapy

Treatment that uses the body's own immune system to fight cancer.

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 even 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.

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 that 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 collaborate to 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.

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.

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 dealing with physical, emotional, cultural, spiritual and social needs. Also known as supportive 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 who are unable to be cared for at home, or don't wish to die at home. It may also offer day care facilities and home visiting teams. Also 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 enduring power of attorney.

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.

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.

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 known as 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.

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 for appointing this person may be called an enduring power of attorney, an enduring power of guardianship or appointment of medical treatment decision maker.

supportive care

See palliative care.

systemic treatment

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

targeted therapy

Drugs that attack specific particles (molecules) within cells that allow cancer to grow and spread.

tumour

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

Can't find a word here?

For more cancer-related words, visit:

- cancercouncil.com.au/words
- cancervic.org.au/glossary
- cancersa.org.au/glossary



How you can help

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

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

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

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

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

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

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



Cancer Council 13 11 20

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

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

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

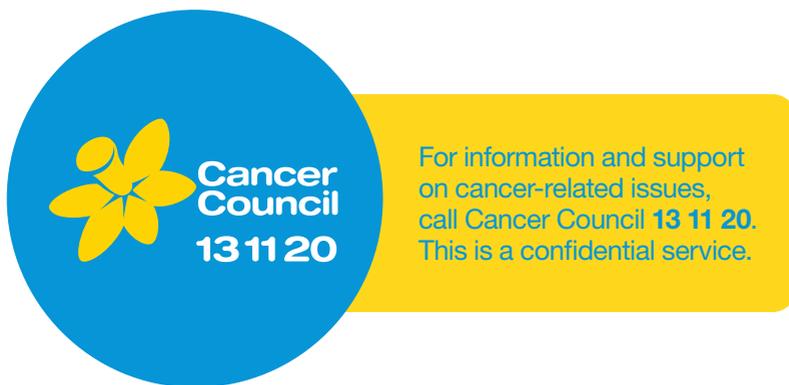
If you are finding it hard to navigate through the health care system, or just need someone to listen to your immediate concerns, call 13 11 20 and find out how we can support you, your family and friends.

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



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

If you are deaf, or have a hearing or speech impairment, you can contact us through the National Relay Service. www.relayservice.gov.au



Produced in collaboration with:



Visit your local Cancer Council website

Cancer Council ACT
actcancer.org

Cancer Council NSW
cancercouncil.com.au

Cancer Council NT
nt.cancer.org.au

Cancer Council Queensland
cancerqld.org.au

Cancer Council SA
cancersa.org.au

Cancer Council Tasmania
cancertas.org.au

Cancer Council Victoria
cancervic.org.au

Cancer Council WA
cancerwa.asn.au

Cancer Council Australia
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.*