



Living with Advanced Cancer

A guide for people with cancer,
their families and friends

Practical and
support
information

Cancer Council Helpline

13 11 20

www.cancercouncil.com.au

Living with Advanced Cancer

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Living with Advanced Cancer is reviewed approximately every three years. Check the publication date above to ensure this copy of the booklet is up to date. To obtain a more recent copy, phone Cancer Council Helpline 13 11 20.

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This booklet is dedicated to Agnes Field. We would like to thank Agnes and her family for sharing their story in the hope of helping others living with advanced cancer.

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Note to reader

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

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

Cancer Council NSW

Cancer Council is the leading cancer charity in NSW. It plays a unique and important role in the fight against cancer through undertaking high-quality research, advocating on cancer issues, providing information and services to the public and people with cancer, and raising funds for cancer programs. This booklet is funded through the generosity of the people of NSW. To make a donation to help defeat cancer, visit Cancer Council's website at www.cancercouncil.com.au or phone 1300 780 113.



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Introduction

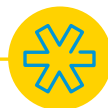
This booklet has been prepared to help you understand more about cancer that has spread from its original (primary) site or has come back (recurred).

Health professionals use several terms to describe cancer that has moved beyond early stages, including secondary, metastatic, advanced and progressive cancer. Sometimes health professionals don't use a particular name. In this booklet, we use the term 'advanced cancer'. Whatever words are used, it can be confronting to hear that the cancer has spread or come back.

This booklet was developed with help from medical experts and people who have been diagnosed with advanced cancer. It offers general information about advanced cancer: what it is, available treatments, what might happen and what support is available. For some people, improved treatments are keeping the disease under control for months or years without curing it (like a chronic disease).

Although it is intended to be helpful, the booklet may stir up difficult feelings. Read the parts that seem useful now and leave the rest until you're ready. You may also like to pass this information on to your family and friends, who may also find it useful.

If you have been told that you are closer to dying, Cancer Council has a booklet called *Facing End of Life: A guide for people dying with cancer, their family and friends*. Call **13 11 20** for a copy.



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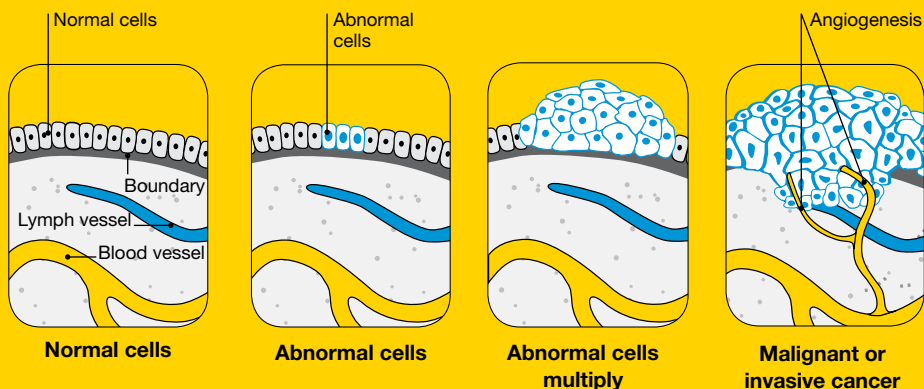
What is advanced cancer?

There are many types of cancer and each type develops differently. Some grow slowly, some advance rapidly, and others are unpredictable in their behaviour. Some types respond well to treatment, while other types are more difficult to treat successfully. Advanced cancer is a term commonly used to describe primary cancer that is unlikely to be cured or secondary (metastatic) cancer that is unlikely to be cured.

Primary cancer refers to the first mass of cancer cells (tumour) that have divided and multiplied uncontrolled in an organ or tissue. The tumour is limited to its original site, such as the bowel. This is known as a cancer in-situ, carcinoma in-situ or localised cancer.

Secondary cancer is when malignant tumour cells from the primary cancer site grow and form another malignant tumour at a new site,

How cancer starts



by moving through the blood or lymphatic system. The abnormal cells divide and multiply and form other masses of abnormal cells (metastases). This is also called metastatic cancer. Secondary cancer can occur if primary cancer is not treated or cannot be treated. Sometimes cancer moves before tests and scans find it.

Advanced cancer usually cannot be cured. However, it can often be treated to slow the growth and ongoing spread of the cancer, sometimes for months or years. Treatment can also help reduce symptoms, such as pain.

Secondary cancer (metastasis) keeps the name of the original, primary cancer. For example, bowel cancer that has spread to the liver is still called metastatic bowel cancer, even though the person may be experiencing symptoms caused by cancer in the liver.

How cancer spreads

Primary cancer

Local invasion

Angiogenesis –
tumours grow their
own blood vessels

Lymph vessel

Metastasis –
cells invade other
parts of the body via
blood vessels and
lymph vessels





Key questions

Q: What happens now?

A: You will need time to deal with the news that the cancer is advanced and to think about things like treatment and practical issues. You may feel overwhelmed at first. It's common to feel as if you're on an emotional roller-coaster. It can help to talk about your emotions and have strategies to cope with them.

Partners, family members and friends can be good sources of support. For ideas on how to cope with your feelings and communicate with those close to you, see *The emotional impact* chapter on page 12.

Q: Who else can I talk to?

A: Some people prefer to discuss their feelings with somebody more neutral or professional. If you want to talk about what will happen in the future, know more about advanced cancer and how it might affect you, or get help with practical problems, start by talking with your general practitioner (GP).

If you don't have a GP you feel you can talk to, you might like to talk with other members of your treatment team. This may include a hospital counsellor, social worker or psychologist.

Support from others going through a similar experience may also be helpful. You could join a face-to-face or telephone support group or an online forum – see page 74. You may also find talking to a religious or pastoral care worker

beneficial. They may be able to offer you comfort and suggest strategies for your practical and emotional concerns.

Q: What treatments are available to me?

A: The type of treatment you have will depend on where the cancer started, how much it has spread and your general health and preferences. The most commonly offered treatments include chemotherapy, radiotherapy, surgery, biological therapy and hormone therapy, or a combination of these treatments.

You can discuss your treatment options with your doctor, as treatment is personalised and important, no matter what stage the cancer is at. Some people may decide that they don't want to have any further active cancer treatment; others feel that palliative care or pain management or rehabilitation would be beneficial. See the *Treatment for advanced cancer* chapter, pages 30–39.

Q: Who is in charge of my treatment?

A: If you have many health professionals caring for you (also referred to as a multidisciplinary team) it can help to know who is coordinating your care. This may be your GP, the palliative care doctor, the oncologist, a care coordinator or another member of the treatment team whom you trust and get on well with.

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

A: Cancer affects people's lives in different ways. You may be able to continue your usual routines for some time. If you work, you may need to take time off or leave work altogether. Your partner or a family member might need to stop work to help care for you.

Treatment or other services can be expensive and may affect your finances and cause concern. This can make it harder to cope with other worries or fears you may have, such as negotiating leave from work or getting financial assistance.

You may experience various symptoms due to the cancer or treatment, such as nausea, fatigue or breathlessness. These may impact on what you can comfortably do for now and your sense of independence. See *Managing symptoms*, page 47.

“There is still a life to be lived and pleasures to be found and disappointments to be had. Living with advanced cancer is a different life, not just a journey towards death.” Julie

There can be practical issues you may have to think about to make life more comfortable, such as medical equipment, alterations to your home or home help. If you have to travel to get to the hospital, you may require transport or accommodation, especially if there are times when you are in and out of hospital.

You may also experience emotional changes from the cancer and its treatment – for example, some hormonal treatments affect people's emotions (and sometimes anger levels). And all the other possible changes to work, care, finances, symptoms may themselves result in emotional changes.

Q: What is palliative care?

A: Palliative care is a combination of services to help improve your quality of life, within the limits of your illness. It can help you to cope with the symptoms of cancer and treatment, as well as the practical problems of daily life.

There is a wide range of services and, at some stage, you will probably use at least one of these. Even if you decide not to have further active treatment for the cancer, doctors and nurses who specialise in palliative care can help relieve or control your symptoms to help you maintain the best possible quality of life. Palliative care can also provide support for families and carers. For more information, see page 33.

Q: Am I going to die?

A: Death can be one of the first things some people think of when they learn they have advanced cancer. Other people's first concern could be how they break the news to their family. This reaction can often be mixed with other feelings, such as fear at the thought of what lies ahead – perhaps pain, loss of control, loneliness and even relief for some.

If you would like to know the expected outcome (prognosis) of the cancer, you will need to talk to your doctor. How long you live for and the changes you may face in that time depend on how the type of cancer you have been diagnosed with behaves and responds to treatment.



For some people, improved treatments can keep the disease under control for months or years without curing it (like a chronic disease).

Palliative medicine can help manage pain or other symptoms associated with cancer and its spread. It can also reduce side effects from cancer treatments to make life more comfortable.

Not all people with advanced cancer die from it – other factors can intervene. Some people do unexpectedly go into remission, with signs and symptoms of cancer no longer present. For other people, different health issues become more serious than the cancer.

When faced with the possibility of dying, some people begin to live day by day. Others find that preparing more consciously for death, such as preparing a will or the funeral, helps them to feel more in control of their life.

If you have questions about dying, call Cancer Council for a free copy of *Facing End of Life: A guide for people dying with cancer, their family and friends*.


Q: What hope is there?

A: If you have been told your cancer is unlikely to be cured, you can still feel hope.

What you hope for may change with time. Sometimes, you may hope for 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 pain-free. Some people explore 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 an excursion with their family.

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. For other people, cancer can test their beliefs. Either way, you may find it helpful to talk to your spiritual or religious adviser, if you have one.

“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



The emotional impact

First reactions

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

If you didn't know you had a primary cancer, a diagnosis of advanced cancer can sometimes feel like a double blow. And if you've already been treated for cancer, you may experience

Feelings you may experience

Fear or anxiety	It can be frightening to hear your cancer has come back, has spread or is at an advanced stage to begin with. Fear or anxiety (a feeling of worry or unease) may occur from the shock of diagnosis; feeling concerned about having less control over aspects of your life; or having thoughts about dying.
Anger	You may be angry because you've had to deal with cancer already or because you weren't diagnosed earlier. Sometimes it may even be difficult to pinpoint exactly what your anger is about.
Guilt	You may 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. Though some people may also feel a sense of hope in the uncertainty.

different, possibly stronger reactions than when you heard for the first time that you had cancer.

Sometimes people feel relieved; you may have suspected something was wrong and now you know what it is. These reactions are all natural. Talking about your feelings with others you trust – even painful feelings – may help you cope with the diagnosis.

Loneliness	You may feel lonely at times even if you have many people around you. It's natural to wonder if anybody else 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.
Denial	An advanced cancer diagnosis can be hard to accept. Denial can give you time to adjust, but it becomes a problem if it stops you from getting treatment or help.
Sadness or depression	People with advanced cancer may sometimes feel sad or depressed. It is okay to feel that you're not coping all the time. But if the sadness lasts longer than two weeks, you're having trouble sleeping or not enjoying things you usually like doing, tell your GP. Counselling or medication can help.
Search for meaning	A diagnosis of cancer often leads people to question their values and priorities, as well as what life means for them.

Ongoing effects

Having advanced cancer often means living with a degree of uncertainty – from the big questions, like how long you might live, to the smaller but still important questions, such as what the next test will show. Learning to live with uncertainty can be challenging, and everyday is likely to be different. Cancer is a personal experience. There is no right way to deal with cancer, but there are different ways to face it, depending on your outlook.

Grief, loss and change

Grief is a natural reaction to any loss or major change that is painful. What you grieve for can be as varied as how you think and feel. An advanced cancer diagnosis can lead to physical, emotional, social, spiritual and financial changes and losses. You may grieve over the loss of what your hopes and plans were for the future, how living with a chronic disease could affect your life (if it restricts your life or independence), or the uncertainty it creates for what lies ahead.

When and how people grieve varies for each individual. You may experience grief at diagnosis, if you start to feel unwell, or during treatment. Its intensity can vary – there may be times when it feels overwhelming. It is possible to find ways of living with the grief. Some people refer to this as finding a ‘new normal’, a way to live life meaningfully while also experiencing the grief. There could be more than one new normal depending on how the disease changes.

A social worker or counsellor can help you and your family deal with grief and loss you may experience.

Feeling down

Everyone reacts to their diagnosis and adjusts to it in their own way and in their own time. Some people may face more challenges with this than others.

It is common to feel depressed following a cancer diagnosis. You may not be able to think as clearly, you may lose interest in things you used to enjoy, or you may not want to get up in the morning at first. While depression is common among people with cancer, it can be treated. Tackling depression early may mean that you can deal with other problems more easily and quickly. Ways to help manage depression can include:

- **Counselling** – Ask your treatment team or call Cancer Council Helpline 13 11 20 for more information. Your GP can help you access the Medicare-funded Better Access initiative, which provides counselling with social workers and psychologists.
- **Medication** – This is helpful for some people. Even if you feel you have good reason to be depressed, medication can help stop depression becoming an additional problem.

For information on depression and tips on overcoming it, contact:

- beyondblue – 1300 224 636 – www.beyondblue.org.au
- Black Dog Institute – www.blackdoginstitute.org.au
- Lifeline 24-hour Telephone Crisis Support – 13 11 14 – www.lifeline.org.au



Being realistic

Some people believe that the attitude of the person with cancer can influence the outcome of the disease. While it can help to be optimistic, this doesn't mean you are denying the reality that cancer is often frightening and challenging. Trying to put on a brave face all the time and avoiding anything painful is hard work – it can drain your energy and may not be a permanent solution as the realities of living with cancer continue.

“ I often think I will scream if one more well-meaning person says ‘Be positive!’ ” Carolyn

Pressure to be positive all the time can 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 you trust about your fears and concerns so that you can better cope with them. Explaining your feelings to those you trust may also help you get the support you need.

Talking to a counsellor or psychologist may also allow you to talk more openly about your concerns and feelings.

Looking for meaning

Everyone has their own beliefs about the meaning of life, and it's quite common for people diagnosed with advanced cancer to re-examine this meaning. For some people, cancer may lead them to change what they think is most important in their lives.

You may want to look for meaning in your life with someone close to you, a spiritual or religious adviser, or a professional, such as a counsellor. If you'd prefer not to talk to someone else, you could write in a journal, meditate or pray.

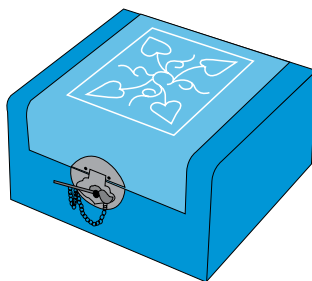
Celebrating your life

Having advanced cancer often gives people a chance to look back on their life and reflect on all they have done. Some people like to share some of the stories of their life with loved ones or prepare something to hand down to family and friends as a memory of themselves, like a legacy.

If you'd like to do this, you could consider writing letters, making a recording of special memories, reviewing or arranging photo albums, writing down your family's history or family tree, making a playlist of favourite songs, gathering favourite recipes into a cookbook or creating artwork.

Memory boxes

Making a memory box is a way to share elements of your life with family and friends. You can choose special items to go into the box that reflect your life, shared experiences and personality. Some ideas include postcards, photos or a list of happy memories.



The effect on people close to you

Family and friends may need time to come to terms with your diagnosis and how they feel about it. They may experience similar fears and anxieties, and need as much information and advice as you. Sometimes family members can feel more distressed than the person with cancer. This seems to be more common when there is a lack of communication.

Another possible reaction is when family or friends stay away or stop contacting you. They may take time to adjust to the fact that things have changed for you. Cancer is also a reminder that life is fragile. When family and friends first hear about the diagnosis, they may block out or ignore things that are too painful to contemplate. You may find this difficult or even hurtful, but it can be a common experience for people with advanced cancer. Other friends may respond with understanding and openness, and become even closer.

Some people will not know how to respond or what to say. Your friends or family may need to take their lead from you. You can guide them on how much you want to talk about the illness and the different issues you want to think about or plan together.



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 email, blogs or social networking sites, or write one letter and have it copied and sent to loved ones. Ask for replies so you know what others are up to.

Getting help

People might be eager to offer help when they first hear about your diagnosis. But it can be a problem if your friends want to do everything for you rather than help you stay independent.

Even when your friends are genuinely willing to help, it can sometimes be hard to ask for their help. Some people will prefer doing practical things for you, such as cooking a meal, shopping for groceries or driving you to an appointment; others may be good at keeping you company.

People you know from your current or past workplace may help by providing updates about what is going on at work, if you want to know or would like the distraction. However, sometimes it might be more helpful if friends and family stay away for awhile.

It may be useful to delegate one friend or relative to coordinate offers of help from other people and to update friends about your progress if you're not able to contact everyone individually yourself.

Home care services may be able to provide assistance with domestic tasks such as cooking and cleaning. For more information, see *Seeking support* on page 74.

“ It is really important to ask for help when you need it – whether it be for practical, financial or spiritual needs. Volunteers, in particular, can offer lots of practical support, as well as friendship. ” Leon



Talking with family and friends

Talking about your feelings can be hard. However, people often cope better with a diagnosis of advanced cancer when they're open with trusted family members and friends about their fears and concerns. There are many issues to think about, and how you talk to others will probably vary, depending on their relationship with you.

Partners

How you communicate with your partner about cancer depends partly on how you've always communicated. Many relationships can be challenged by a cancer diagnosis. At times, you and your partner may not share each other's feelings, attitudes or opinions.

When it feels like the right time, sharing your feelings openly and honestly can help support you both through your anxieties, sadness and uncertainty.

There may be role changes for each of you. Your partner may try to protect you by doing everything for you. Or you may not be able to do things you used to do, which can lead to feelings of frustration and helplessness or changes in your sense of independence. These feelings are common for people with advanced cancer.



In this booklet, the term 'partner' means husband, wife, girlfriend, boyfriend, same-sex partner etc.

It can help if you feel involved at home and with the family, even if you can only do small tasks and need to pace yourself.

You may find it difficult and painful if your partner doesn't want to face what is happening and can't talk about it with you or help you make decisions about treatment.

When things are tough, it may help if you tell your partner what you need most from them. Many people say that their biggest single need is for a sympathetic listener. It might help to remind your partner that the important thing is not what to say – but to be there and to listen.

Body image

Your body will probably change. You might find it hard to accept how you look and think that others will also struggle to accept your body.

Weight loss is common, and if you have treatment such as chemotherapy or radiotherapy you may feel and look fatigued.

Weight gain from steroid treatment can also change how you look and be hard to accept.

Most partners, however, are accepting of these changes. If you feel down about your body, think about all your inner qualities, such as kindness, warmth or a sense of humour, and your different abilities, which are just as important as your physical features.

It might also help to discuss your concerns with your partner, as they may be able to reassure you.

Sexual intimacy

We are all sexual beings, and intimacy adds to the quality of our lives. Sex may have been a big part of your life or you may value physical contact, such as hugging or holding hands, as much as sexual intimacy. Usually sex and intimacy is safe for you and your partner but if you have concerns, check with your doctor or nurse.

There may be times when it is difficult for you and your partner to have the kind of closeness you would like. Depending on where the cancer has spread, or the type of treatment you're having, you can feel sore all over and not tolerate even a gentle hug.

Some people with cancer avoid physical contact for fear of rejection. And partners of people with cancer sometimes avoid physical contact for fear of hurting their partner.

It takes time to adapt to physical and emotional changes. Most people find it is easier to re-establish contact by starting with simple things, such as lying close together in bed. Some people find holding hands becomes an expression of closeness.

If these first steps are hard, ask your doctor or nurse counsellor to suggest ways to help make sexual intercourse easier. If this is no longer possible or desired, you may find physical closeness in other ways, such as cuddling, stroking or massage.



Call Cancer Council Helpline **13 11 20** for a free copy of the *Sexuality, Intimacy and Cancer* booklet.

Physical and emotional intimacy

Physical and emotional intimacy can keep you going through difficult times. A sense of closeness can come unexpectedly. A timely kiss from a child, a hug from a friend, or a caring touch from a nurse as they talk to you could make all the difference to your day.

Parents

It can be a painful experience to be the parent of someone with advanced cancer. Most parents feel it goes against nature to outlive their children. Your parents are likely to feel overwhelmed with sorrow and helplessness at first. It may take them a while to adjust. Information about your condition may help your parents or your grown-up children cope with their own feelings.

Friends

You may find your friends are invaluable, especially if your family is not nearby or helpful. Sometimes an advanced cancer diagnosis occurs when your family relationships are shaky. Even if some of your friends can't deal with your diagnosis, there will be others you can lean on for emotional and practical support.

Some friends can listen to whatever you say – complaints, hopes, fears, wishes – without judging you and without that extra involvement that a partner or relative may feel is necessary.

Children

Children need explanations that they can understand. If you've explained cancer and its treatment before, it might be easier to start the discussion. However, you might find it harder to talk about the cancer advancing and being difficult to cure.

Young children

Even if they are young, your children will probably suspect that something is wrong. They may notice changes at home, such as your distress or an increase in visitors.

Assure children that the disease is no-one's fault. Children may think they, or their behaviour, caused the cancer. They might also fear the same thing happening to them or someone else they know.

Children will want to know in advance when you will be staying in hospital or needing rest at home. They will want to be reassured that there will always be someone to care for them.



If you are a sole parent, finding someone to look after your children may be harder. It may help to talk to a social worker about what's available in your local area.

Teenage children

Teenagers react in different ways, ranging from withdrawal to offers of help and assurances of love. Like younger children, teenagers can feel abandoned as the family focuses on the sick person. Instead of focusing on themselves, teenagers are

now confronted with the needs of the family. Because of these pressures, there may be outbursts over trivial things. They may also react to feelings that they are not really aware of, or cannot acknowledge, like anger, guilt or grief.

As with younger children, teenagers need to keep as much of their normal routine as possible – school, homework, outings and holiday activities. This may be difficult to manage when you're feeling unwell and is particularly hard if you are a single parent. If you're living with a partner, they may need to keep working as well as caring for you. This can leave little energy for children's needs.

Adult children

Adult children may struggle when they find out you have advanced cancer. They can become aware of their own desire to have a parent around forever. They may feel guilty because they can't meet the different demands on them as parents, children and employees.

You might feel you have to, or want to, carry on as the head of the family, reassuring everyone that things are the same as always. Having to rely on your adult children more and more may make you feel guilty.

tip

For more information and tips on discussing cancer with children, call Cancer Council Helpline **13 11 20** for a free copy of the book *Talking to Kids About Cancer*.

What to say to family and friends

Young children

- Listen and be alert to their feelings, this gives you an idea of what they can handle.
- Communicate feelings as well as facts.
- Give simple, honest answers, and clarify any confusion.
- Explain what will happen next and give children realistic hope – e.g. that the family can still enjoy time together.
- Don't make promises you may be unable to keep.
- Try to keep family routines as normal as possible.
- Give children extra reassurance. They may become clingy or withdrawn – both are natural reactions.

Teenage children

- Give people who offer to help out with the children a specific task that benefits your child, such as taking them to sport or helping out with homework.
- Encourage them to talk about their feelings, but understand they may find it easier to confide in friends, teachers or other trusted people.
- Organise a break from home, e.g. a sleepover at a friend's or a regular night out with peers.
- Provide resources for learning more about cancer and getting support, such as the websites www.myparentscancer.com.au and www.nowwhat.org.au.

Adult children

- Consider involving your adult children in decision-making about treatment or activities you want to continue. They may have valuable input.
- Talk about ways your children might be able to help you, while still being able to manage the other priorities in their life.
- Provide information about your condition to your grown-up children to help them cope with their feelings.
- Organise or make time to spend with your children so you can create meaningful memories together.

Parents

- Give parents time to grieve and express their emotions.
- Explain current treatments. This may lessen any fears from their past experiences with cancer.
- Provide information about your condition to help your parents cope with their own feelings.

Friends

- Ask friends to help – they'll probably be glad to do something for you.
- Connect with others – try online forums when it's hard to leave the house, if you live far away from friends or family, or if you aren't able to join a cancer support group. Visit www.cancerconnections.com.au.

When you don't want to talk about it

You may not want to talk about your fears and concerns with family and friends. This may be because you think you don't have the words to describe how you feel, or you fear breaking down if you speak. You may also want to avoid being a burden to others or fear appearing as if you are not coping or you may just be a very private person.

Tips for opening up to others



Let others help

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



Talk about your concerns

Talk about your fears and concerns with others, even if you break down at first, it often becomes easier with time.

Join a support group, talk to a health professional or call Cancer Council Helpline **13 11 20**.



Express your feelings creatively

Explore your feelings by writing in a journal or making something creative like an artwork or a song. This can help you to release your emotions if you find it difficult to talk to others.

Euthanasia

If an illness is prolonged or very debilitating, some people think about euthanasia. This is when somebody's life is deliberately ended to relieve them of their suffering from an incurable condition or illness.

Euthanasia is illegal in every state and territory in Australia. Nevertheless, it is something that many people consider when they are seriously ill.

Discuss your feelings and concerns with your doctor, family, friends, a counsellor or social worker. Sometimes these feelings are the result of depression or feelings of hopelessness, guilt or

loneliness. These feelings can be helped with counselling and/or medical treatment.

Sometimes a person with cancer may decide that they want their death hastened, but later they decide that they don't. They may have thought that way because they were feeling particularly ill, scared, or worried about the strain they were putting on others.

If you urgently need somebody to talk to because you are thinking about ending your life, call Lifeline on **13 11 14** for free, confidential telephone counselling at any time of the day or night.



Treatment for advanced cancer

Some people believe that nothing more can be done if they receive a diagnosis of advanced cancer. However, treatment can keep some advanced cancers under control for months or years. In other cases, palliative care can help to control and relieve symptoms such as pain, fatigue or digestive problems.

Although most advanced cancers can't be cured, something can almost always be done to help maintain or improve your quality of life. 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 other options. Also, ask if you are eligible to be part of a clinical trial (see page 46).

Some people with advanced cancer use the internet to thoroughly research proposed treatments. The internet can be a useful source of information, but not all websites are reliable. You can check the accuracy of information you find online with your doctor or Helpline. A list of reliable websites can also be found on pages 80–81.

This section explains the treatments that can ease the symptoms of advanced cancer or keep disease progression under control.



For more information on the different types of treatments available for advanced cancer, call Cancer Council Helpline **13 11 20** and ask for free resources on chemotherapy, radiotherapy or palliative care.

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 2–3 weeks. Most people usually have several courses of treatment.

The chemotherapy drugs are usually given by injecting the drugs into a vein (intravenously), but can also be given 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 of chemotherapy can include nausea, depression, tiredness and hair loss. Many of these are temporary and can be prevented or reduced. Different types of chemotherapy have different side effects – for instance, not all of them cause hair loss.

Surgery

Surgery can remove tumours from affected areas, for example the bowel or lymph nodes. It can also relieve discomfort caused by tumours that obstruct organs or cause bleeding, such as unblocking the bile duct to relieve jaundice in pancreatic cancer.

Your doctor might suggest surgery on organs that stimulate tumour growth because of the hormones they release, for example, removing the testicles to reduce testosterone levels and slow the growth of prostate cancer.

Radiotherapy

Radiotherapy uses radiation, such as x-rays, to kill cancer cells or injure them so that they cannot multiply. This can be precisely targeted at cancer sites in your body. Treatment is carefully planned to do as little harm as possible to your normal body tissues.

Radiotherapy can shrink tumours or stop them from spreading further. It can also relieve symptoms such as pain from secondary cancer in the bones. External beam radiation or internal radiation (brachytherapy) may be offered.

Side effects from radiotherapy can include fatigue, skin problems or loss of appetite. These may be temporary or longer lasting.

Hormone therapy

Cancer that grows in response to hormones can often be slowed by taking drugs to suppress the body's production of the hormone. Other treatments interfere with the effect of hormones on tumour cells.

If you have prostate, breast or uterine cancer, you may be offered hormone therapy. This may cause some side effects.

For women, certain hormonal drugs will cause menopausal symptoms, regardless of your age. Hormonal drugs called aromatase inhibitors may be used if you have been through menopause, and these may cause thinning of the bones (osteoporosis) and vaginal dryness. For men, hormone treatments can produce hot flushes.

Palliative care

Palliative care allows people with advanced cancer to maintain their quality of life. It helps you cope with the symptoms of cancer or its treatment, as well as the practical problems of daily life.

Many people think that palliative care is just for people that are dying, but it is appropriate at any stage of advanced cancer. People can receive palliative care for many months or even years.

Palliative care also involves spiritual care and the support of relatives and carers. It incorporates a range of services offered by medical, nursing and allied health professionals, as well as volunteers and carers.

You can have palliative care while you are having active treatment.

What palliative care workers do

- provide relief from pain and other distressing symptoms to maintain your quality of life, without prolonging or shortening life
- help you feel in control of your situation and make decisions about your treatment and ongoing care
- coordinate your care and treatment with your treatment team – they do not take over treatment and care
- offer support for families and carers during your illness
- make the time you have as valuable as possible for you and your family

Contacting the palliative care team early in your illness means that you can find out what the different team members do to 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. If you are not linked in with a palliative care service and would like to be, speak to your doctor or nurse.

Palliative care units

A palliative care unit or hospice provides inpatient and outpatient care to people with a limited prognosis. The palliative care unit has hospital facilities but a home-like atmosphere. The staff are specially trained in palliative care.

A person may go into a unit to have pain or other symptoms, such as severe constipation or breathing difficulties, brought under control. They may also go there to give the person caring for them a break (respite care).

Many people go into a palliative care unit for a short time, for instance, about a week. This may be until

symptoms are under control and family or carers feel confident to resume their supportive role.

You can also receive palliative care in your home. A palliative care service can coordinate all your medical, practical, social, emotional and spiritual needs.

This service is mostly free. There may be charges for some services, such as hiring specialised equipment, massage therapy or nursing staff for home.

Call **13 11 20** for more information about palliative care, how to access it and how it can benefit you.

“ 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*

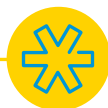
Rehabilitation

It is frustrating to find that cancer can limit your activities. Rehabilitation is a way of improving your quality of life between or after treatment. It may involve restoring physical functioning with the use of 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 can also organise rehabilitation for you.

For more information on the availability of rehabilitation services in your area, contact Cancer Council Helpline **13 11 20** or the Commonwealth Rehabilitation Services on **1800 277 277** or visit www.crsaustralia.gov.au.



Complementary and alternative therapies

Many people with advanced cancer want to know more about complementary and alternative therapies. They may seek therapies to help with different symptoms and side effects, or they may hope to find a cure for the cancer. Often, people want to feel that they've tried every available option. For many people, complementary or alternative therapies give them a sense of control.

“ I was given three months to live. I was a mess, but decided my lifestyle, diet, mental attitude and work needed to be modified anyhow. ” *Richard*

Complementary therapies

Complementary therapies are sometimes called natural therapies. They can be used in combination with conventional medicine, such as chemotherapy or radiotherapy. Therapies include acupuncture, massage, hypnotherapy, herbal medicine, nutrition and relaxation. These may help you cope better with side effects and feel as well as possible. They may also reduce your feelings of helplessness, stress and anxiety.

Some complementary therapies may reduce the amount of medication needed for pain control. Many people benefit from relaxation techniques, meditation and hypnotherapy. Massage can also be a great release, but check with your medical team if there are areas of your body that are too fragile to touch. Your massage therapist will need to make adjustments for you.

While some cancer treatment centres and palliative care units offer complementary therapies, such as massage, meditation or art therapy, as part of their services, you may have to see a private practitioner. If you go to a private practitioner and have private health insurance, check if your health fund provides a rebate.

Most complementary therapies cost money, but some community centres offer group therapies, for example tai chi or yoga, for free or a small charge. You can also use self-help CDs or DVDs to guide you through techniques. Call 13 11 20 for more information on complementary therapies, meditation or relaxation.

Let your doctor know if you plan to use complementary therapies. This is important, as some therapies may not be appropriate, depending on your conventional treatment or what is happening in your body. For example, some herbs and nutritional supplements may interact with your medication, resulting in harmful side effects.



Alternative therapies

Alternative therapies are commonly defined as those treatments used instead of conventional medicine. Many alternative therapies claim to stop cancer growing and to cure the disease, but they are not scientifically tested or proven to be effective.

When cancer has spread and you've been told there's no cure, one reaction is to reject regular medical treatment, feeling that it has failed you. You may hope that an alternative therapy offers a cure.

However, some alternative therapies can be harmful – for example taking high-dose vitamins or eating an unusual diet that doesn't provide all the nutrients you need. Some may also be costly despite having no effect. Be wary if any treatment:

- claims to cure all cancers
- costs a lot of money or requires you to travel overseas
- claims the medical/pharmaceutical industry wants to stop its use
- requires major changes in lifestyle
- claims to have positive results with few or no side effects.

Information on alternative therapies is available from many sources, such as books and the internet. Friends and family may also tell you about cancer cures they've heard of. Some of this information may be confusing or wrong. Try and think carefully about it and find supporting information from other sources. Ask questions, and only go to a qualified, trustworthy practitioner.



Check with your doctor if you're planning to use alternative therapies to make sure they won't cause any harm.



Key points

- Improved treatments mean that some advanced cancers can be kept under control for months or years, like a chronic disease.
- If your current treatment is no longer working or the side effects are hard to cope with, ask your doctor about other options. New drugs are constantly becoming available.
- There are different types of treatment for advanced cancer that may be used separately or in combination.
- Chemotherapy is the most commonly used treatment when cancer has spread.
- Surgery can be used to remove tumours that might be causing symptoms such as pain.
- Radiotherapy is used to kill cancer cells or injure them so that they cannot multiply. It is also used to relieve symptoms such as pain.
- Hormone therapy is used for cancer that grows in response to hormones. It can slow tumour growth.
- Palliative care helps you cope with 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 between or after treatment.
- Let your doctor know if you plan to use complementary or alternative therapies to make sure they do not result in harmful side effects.



Making treatment decisions

There is no right or wrong decision when it comes to your care. Some people with advanced cancer will always choose treatment, even if it only offers a small chance of improvement. Others want to make sure the potential benefits of treatment outweigh any side effects, or they want to choose the option they consider offers them the best quality of life.

Some people decide not to have active treatment for the cancer, but to have symptoms managed to reduce pain and discomfort, and to increase their independence as much as possible.

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 treatment.

It is sometimes very difficult to make these treatment decisions. Organising your thoughts on paper can be easier than trying to do it in your head. Consider all the options available to you and write down any questions you have about your treatment choices. Your family and medical team may help with these decisions, but check that the decision you make is what you would like to happen and not what you think is best for family and friends.

“My wife had a second operation (contrary to the surgeon’s advice). In hindsight, she said she did it for the family but that it was a mistake.” Philip

When treatment seems too much

To cure a primary cancer, it can seem worthwhile undergoing harsh or disfiguring treatments. But when a cure is unlikely, it may seem less reasonable to choose treatments that leave you feeling exhausted or sick, even if they will help you to live longer.

- Before you start or stop treatment, think about the pros and cons. Rarely do decisions have to be made on the spot.
- Ask yourself if you are feeling unwell from the side effects of the treatment, from the advancing disease or from emotional overload. Some or all of these can be treated.
- Talk with others, particularly your doctor and those close to you. Their input and support may help clarify your thoughts.
- Speak to someone less closely involved, 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 say no to any treatment offered. For your refusal to be accepted, you must understand the nature of the treatment proposed and the consequences of not having it. You can refuse each treatment separately – you do not have to accept treatment on an all-or-nothing basis.

In some states and territories you can complete a refusal of medical treatment certificate, outlining your wishes, which your treating doctors must follow. See *Advance care directive*, page 59.

Agnes' story

It was 1984 when I made an appointment with my GP – I had the flu so it was a routine check-up. However, during the examination he found a lump in my breast. He was concerned because it was a large lump, so I was rushed to tests and scans. When I was diagnosed with breast cancer, it was a big blow.

The doctors advised I have a double mastectomy, but I chose not to go through with the operation. However, I was given chemotherapy and radiotherapy.

It was a very difficult period of time for me. My husband and I had two young children, aged 5 and 10, and our marriage ended shortly thereafter.

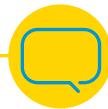
My family was also spread over Australia and New Zealand. Mum came over to look after my children, but she died just after I started

chemotherapy. This was a very sad time for me. I stopped treatment to organise her funeral.

After this, I felt like I didn't have anybody. It was a struggle to support my children. I had to work three jobs to get by. I was also struggling with the side effects from treatment, such as headaches, memory loss, fainting and diarrhoea.

I finished active treatment but was taking tamoxifen continuously for many years. However, over time, the cancer came back into my lungs, liver and bones.

It was over 20 years ago 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.



Around this time, 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, 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.

Talking with doctors

Some people find it hard to talk openly with the different doctors on their treatment team. You might be concerned about taking up too much time, or your doctor might give the impression of being rushed. It usually takes time for information to sink in and even more time to think over the choices being offered.

If your doctor uses medical terms you don't understand, it's okay to ask for a simpler explanation. You can also check a word's meaning in the glossary on page 84.

It is important that you know who is coordinating your care if you have many health professionals caring for you (a multidisciplinary team). As you go from one doctor to another, you might wonder who is responsible for what. It saves time and trouble if there is one person keeping track of your situation. This may be your GP, the palliative care doctor, the oncologist, a care coordinator or another member of the treatment team.

Let your doctor know if you are finding it difficult to talk, even after several visits. Most doctors want to be able to communicate well with their patients – it helps them too. However, it can take time to establish a good relationship.



Find out how, and in what situations, you should contact your doctor. When an unexpected problem arises, it can add to your stress if you're confused about who you should call.

tips

- Prepare a list of questions before your appointments and let your doctor know early on that you have questions. See pages 82–83 for a list of suggested questions.
- Ask for a longer appointment in advance, especially if you have many things to discuss.
- Keep a file of your test results and scans, as well as a record of any symptoms and side effects, and take these with you to appointments.
- Ask the doctor to explain an answer differently, if you don't understand.
- Take notes or record the discussion. You can also ask a family member or friend to go with you to take notes or simply listen.
- Consider looking for another doctor, if you feel you don't have good communication with the doctor treating you.

A second opinion

Getting a second opinion from another specialist may be a valuable part of your decision-making process. It can confirm or clarify your doctor's recommendations and reassure you that you have explored all of your options. Some people feel uncomfortable asking their doctor for a referral for a second opinion, but specialists are used to people doing this.

Your doctor 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. Alternatively, you may decide you would prefer to be treated by the doctor who provided the second opinion.

Taking part in a clinical trial

Your doctor may suggest you consider taking part in a clinical trial. Research teams run clinical trials to test new or modified treatments and ways of diagnosing disease to see if they are better than current methods. There are trials for all sorts of treatments, including chemotherapy, radiotherapy and medications. Some trials also look at how well treatments control symptoms or whether they improve quality of life.

If you join what is called a randomised clinical trial for a new treatment, you will be chosen at random to receive either the best existing treatment or the promising new treatment.

To help you decide whether or not to participate, you can talk to your specialist or the clinical trials nurse. If you're still unsure, you can also ask for a second opinion from an independent specialist. If you do decide to take part, you have the right to withdraw from the trial at any time; doing so will not jeopardise your ongoing treatment for cancer.

How to find a suitable study

For more information about clinical trials and other research, including questions to ask your doctor and how to find a suitable study, download the booklet *Understanding Clinical Trials and Research* from your local Cancer Council website or call Cancer Council Helpline **13 11 20**. You can also find trials on the website www.australiancancertrials.gov.au.



Managing symptoms

People experience many different symptoms when they have advanced cancer. Common symptoms include pain, nausea, a lack of appetite, breathlessness and tiredness. As the disease progresses, these symptoms can vary in intensity and frequency, placing different limitations on your body.

Pain

Many people with advanced cancer worry they will be in pain. Not everyone will experience pain as the cancer progresses, and those who do may find their pain comes and goes. Pain depends on the location of the cancer and its size. If you do experience pain, it can usually be controlled. Pain management is recognised as a specialised field for doctors and nurses. Palliative care services specialise in pain management.

There are many ways to relieve pain, including:

- pain medications such as paracetamol, non-steroidal anti-inflammatory drugs (NSAIDs), codeine and opioids
- a pain-relieving nerve block procedure
- relaxation techniques such as massage, meditation, yoga or hypnotherapy (see page 36)
- treating the cause of the pain with chemotherapy, radiotherapy or surgery.

tip

There may be times when you need immediate advice about your symptoms. Find out which doctor or nurse you can contact at any hour of the day or night for urgent advice.

“ I found the decision to take morphine regularly difficult. Having made it, I have been taking the slow-release tablets for 18 months with no appreciable side effects. Without the morphine, the pain would be too debilitating for me to continue doing all the things I do now. ” *Pete*

You may need to use more than one of these pain-relieving methods. And it may take time to find the right pain-control measure for you. If something doesn't work, there may be other things you can try – ask your doctor to discuss these options.

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 medication regularly, rather than waiting for the pain to build up.

Pain-relieving medication

Medications that relieve pain are called analgesics. They may be mild, like aspirin, paracetamol or non-steroidal anti-inflammatory drugs (NSAIDs) or relatively strong, like opioids.

Pain medications may be taken as tablets, other oral mixtures, suppositories, patches and injections, or self-regulating pumps.

The pain specialists will assess your needs to work out the right drug, its dose, and how it will be delivered (for example, if you have a tablet or injection). They also help you control any side effects caused by the pain medication, such as constipation.

Make sure you understand how much medication you should take and how often (the dosage). A diary/instruction sheet can often help, and examples can be found in the *Overcoming Cancer Pain* booklet. Call Cancer Council Helpline for a free copy.

Opioids

Morphine is one of the most common opioid drugs used to control moderate to severe cancer pain. It is very effective and comes in quick-acting and long-acting forms. It can be taken for a long time, in increasing doses if needed. It doesn't have to be only for when the pain is really bad.

Many people are concerned about taking opioids. However, addiction is not a major concern when morphine is taken to relieve pain. Morphine is most effective when taken regularly. It is better to treat the pain early than wait to treat the pain when it builds up. People usually experience side effects when they take morphine, most of which settle down after a few days.

Managing morphine side effects

Drowsiness	This decreases after a couple of days so you can carry on normal activities and be pain free.
Nausea	If you have difficulty tolerating morphine because of the nausea it causes, you may have to change medication. See page 54 for ways to cope with nausea.
Constipation	This can be prevented by taking laxatives regularly.

Chemotherapy, radiotherapy and surgery

Even though they may not be able to cure the cancer, chemotherapy, radiotherapy and surgery are used to reduce pain from advanced cancer.

Chemotherapy – can shrink cancer 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.

Radiotherapy – can relieve some types of pain, for example headaches caused by increased pressure in the brain due to cancer that has spread from another part of the body (brain metastases).

Surgery – can remove a single tumour in the soft organs; treat a serious condition like a bowel obstruction that is causing pain; or improve outcomes from chemotherapy and radiotherapy by reducing the size of a tumour.

Nerve block

You may have a nerve block if cancer is affecting the nerves and causing pain. A block is when the nerves are directly targeted with pain-relieving medication.

A pain specialist or an anaesthetist usually performs the nerve block procedure. The affected nerve is injected with a drug, such as a local anaesthetic. This makes the nerve unable to send pain signals to the brain. The pain relief is usually temporary; how long

it lasts will depend on the type of drugs used. The medication chosen to block the nerve depends on the nerve involved and its role in the body. A nerve block may be used if other pain control methods are unsuccessful. It is usually used in combination with other medications, such as analgesics or antispasmodics.

Feeling sick

Feeling sick in the stomach (nausea) is an unpleasant symptom that can be caused by treatment with chemotherapy or radiotherapy or the location of the cancer.

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. You don't have to put up with nausea. Tell your doctor or nurse so they can identify the cause and give you the right treatment. They may prescribe anti-nausea medication or suggest dietary changes.

Feeling nauseous may also be a symptom of high levels of calcium in the bloodstream (hypercalcaemia). This is more common in certain types of advanced cancer and there are many other symptoms. You may need a drug that lowers calcium levels in the blood.

“ At first I couldn't think about eating without thinking about throwing up. Drinking ginger beer helped control the nausea. ” Simon

Lack of appetite

People with advanced cancer often experience a lack of appetite. This can result from the illness, treatment, tiredness, an altered sense of taste, pain, lack of activity, depression, nausea or vomiting.

You may go through periods of not wanting to eat. This may last a few days or weeks or it could be ongoing, you may just be unable to eat the way you used to. There are ways to make mealtimes more appealing if you have lost your appetite, see page 54.



Read Cancer Council's *Nutrition and Cancer* booklet for tips on dealing with nausea and lack of appetite. Call **13 11 20** for a copy.

Trouble breathing

Some people with advanced cancer experience trouble breathing or breathlessness. You may find the feeling of being breathless quite frightening. Feeling anxious can make breathlessness worse. Let your doctor or nurse know if you feel like this as there may be treatment that helps.

Shortness of breath can be caused by:

- fluid surrounding the lungs
- having an infection
- the cancer itself
- scarring from radiotherapy
- pressure from a swollen abdomen
- chronic breathing disorders such as asthma or emphysema.

Treatment will depend on the cause of the breathlessness. You may need your lungs drained or medication prescribed to treat an infection or other lung problem. Opioids can ease the distress of shortness of breath, just as they ease the distress of pain. Side effects may include constipation and drowsiness. If breathlessness is ongoing, you may be offered portable oxygen.

Tiredness

For many people, extreme or constant tiredness (fatigue) can be a major problem. It can be very distressing for the person experiencing it and for those around them. Some people say their tiredness is worse than any pain or nausea they experience.

Tiredness 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 radiotherapy
- inadequate nutrition causing 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. The cause may be something treatable, like anaemia or a mineral imbalance. You may be referred to an occupational therapist who can show you techniques for conserving your energy.

Feeling sick

- Eat small meals or snacks as often as you can.
- Eat cold foods such as sandwiches, salads, stewed fruit or jelly.
- Have food or drink with ginger, e.g. ginger ale, ginger tea or ginger cake.
- Take anti-nausea medication regularly, before both eating and pain medication.
- Avoid strong odours and cooking smells.
- Use stress reduction techniques, such as meditation.

Lack of appetite

- Prepare snacks and meals for times when you don't feel like cooking.
- Eat with friends and family to help you eat more.
- Use small dishes so food isn't lost on the plate, such as soup in a cup or dessert in a glass.
- Eat foods you enjoy. Treat yourself to your favourite foods or what you feel like, no matter what time of the day.
- Add ice-cream or fruit to a smoothie to increase calories and nutrients.
- Choose full-fat foods as much as possible.
- Use lemon juice, salt, herbs and spices to flavour bland food.
- Sip on juice, cordials, soft drinks and sports drinks during the day to keep hydrated.
- Add protein foods to fruit and vegetables, e.g. fruit and yoghurt, dip with roasted vegetables and olive oil.

Trouble breathing

- Sit up to ease your breathing or lean forward and rest on a table; avoid bending down.
- Wear loose clothing around your waist and chest.
- Use a fan or open a window to increase airflow near your face.
- Stay as active as you can to help maintain your strength.
- Try not to do too much at once. Pace activities during the day or break them up into smaller tasks.
- 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.
- Get all your clothes ready and have them in one place before you shower or bathe.
- Try to relax or practise breathing techniques.

Tiredness

- Set small, manageable goals.
- When you plan your day, include rest times and plan to do things at the time of day when you feel less tired.
- Try gentle activities, such as walking to the letterbox, doing stretches or getting out of bed for meals.
- Avoid stress where possible – relaxation techniques can help.
- Keep a record of how you feel during the day.
- Have several short naps rather than one long rest period.
- Limit the number of visitors you have if they are tiring you.
- Eat well and drink plenty of fluids. A dietitian can help you change your eating habits.
- Limit the amount of alcohol you drink. Alcohol can cause tiredness and energy loss.



Key points

- People with advanced cancer can experience a wide range of symptoms, which may change over time, placing different limitations on your body.
- You may experience pain, but it will depend on the size and location of the cancer and it can usually be controlled.
- Pain-relieving medication (analgesics) can be mild, like aspirin, or relatively strong like opioids.
- There are pain specialists who can assess you and your needs to work out the best drug, dose and delivery.
- Morphine is one of the most common opioid drugs used to control moderate to severe pain from cancer.
- It is better to treat the pain early than wait to treat the pain when it builds up.
- Chemotherapy, radiotherapy and surgery can be used to reduce pain from advanced cancer.
- A nerve block procedure will often be carried out if cancer is affecting the nerves, but the pain relief from this is usually only temporary.
- Chemotherapy, radiotherapy or the location of the cancer can make you feel sick (nauseated).
- You may also experience a lack of appetite. Try to find ways to make mealtimes more appealing.
- If you experience trouble breathing or breathlessness, let your doctor know, as there may be treatment that helps.
- Constant tiredness can be distressing. If you feel it is getting worse, tell your doctor. It may be caused by something treatable.



Getting your affairs in order

Organising your personal, financial and legal affairs, collecting all the paperwork and making decisions you may not be ready for, such as writing your will or choosing the type of funeral you would like, can be hard. However, doing this can bring a sense of relief and can allow you to focus on treatment and living.

Talk to your lawyer or a financial planner about your specific legal and financial situation, as rules and regulations differ for each state and territory in Australia.

Organising your paperwork

It's a good idea to have all of your paperwork in one place. This will make it easier if, for example, you need to be in hospital for a long time and a family member has to help you with financial and legal matters. Important documents to get together might include:

- birth, marriage and divorce certificates
- bank and credit card information
- investment details
- Centrelink and Medicare details
- superannuation and insurance information
- funeral information
- house title/lease documents
- will
- passport.

Discuss your legal arrangements with your family, and tell someone close where you keep your legal documents or how to contact your lawyer.

Making your will

A will is a binding document outlining who should receive your assets (possessions and property) after your death. These assets are called your estate. A will authorises a person (your executor) to act according to your wishes and to administer your estate.

If you do not write a will, the law provides guidelines on how your estate will be distributed. This can cause further financial and emotional stress for family members at an already difficult time. If you already have a will from before the cancer diagnosis, you may want to review it to make sure it reflects your current wishes.

Appointing a substitute decision maker

You can appoint someone to make decisions for you if at some point in the future you're not able to make them yourself. This can include decisions about your finances, property, medical care and lifestyle. This person, called a substitute decision maker, should be someone you trust, who will listen carefully to your values and wishes for future care. You need to be an adult and have capacity (see opposite) when you appoint this person.



Depending on where you live, the documents used to appoint a substitute decision maker have different names. These can include an enduring power of attorney, enduring power of guardianship or appointment of enduring guardian.

Advance care directive

Your doctor or another health professional may recommend that you think about making an advance care directive. In some states and territories the advance care directive is referred to as an advance health directive, advance care plan or living will. This document outlines the medical treatment you do or don't want to have.

An advance care directive can provide you, your family and carers the opportunity to take control of decisions that affect your care, if at some point in the future you no longer have the capacity to make them yourself.

You can make the advance care directive as simple or as detailed as you like. If you have religious beliefs that may affect your health care decisions, you can record these in your advance care directive. You need to be an adult and have capacity to make an advance care directive.

Having capacity to sign a legal document

When you make a will, appoint a substitute decision maker or write an advance care directive, you need to be an adult and have capacity at the time of signing a 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. If there could be any doubt about your capacity, it's a good idea to get a doctor's certificate to verify this.

What to do with your advance care directive

Keep a copy of your advance care directive for yourself and also give copies to your GP, oncologist, substitute decision maker, solicitor and a family member or friend. You can ask your doctor or the hospital to place the plan on your medical record.

Superannuation

Accessing superannuation early

There are grounds for accessing your superannuation (retirement fund) early, such as to help cover the costs of medical treatment, severe financial hardship, or if you are diagnosed with a terminal illness. For more information visit the Australian Government Department of Human Services at www.humanservices.gov.au.

Finding missing superannuation

To find any missing or forgotten funds, contact the Australian Taxation Office (you will need your tax file number ready) and ask them to search for it. Check that you have nominated a person to receive your benefit upon your death, known as a death benefit nomination with your superannuation fund. Visit www.ato.gov.au or call 13 10 20.

Insurance

Often people don't know that they have insurance attached to their superannuation. Many funds offer insurance by default. Common types of insurance provided can include income protection, total and permanent disability and death cover.

Dealing with bills and debts

There is help available if you are having difficulty paying your utility bills, such as water, gas and electricity. Options include flexible payment arrangements or there may be discounts, rebates or concessions available.

Check with the hospital social worker what options are available in your state and territory.

This is only an introduction to these topics. Cancer Council's book *When Cancer Changes your Financial Plans* has more detailed information, and there are also fact sheets available in many states and territories. Call Helpline for these free resources.



Planning for your funeral

You may wish to plan your funeral or memorial service so that it will be conducted according to your wishes and so your family won't have to guess what you would have wanted.

- Some funeral directors accept payment in advance and some insurance companies have funeral payment plans.
- You can lodge a plan with the funeral director of your choice well before it is needed.
- You may have a few simple requests for music to be played or poems read, or you may have ideas for the full program.

- It can be difficult, but you may also like to write out your wishes or discuss them with your family.
- If what you wish to happen changes, you can change these arrangements at any time.
- If you feel you need to make preparations but you can't do all the work, or prefer not to, talk to a social worker or pastoral care worker who can help you work out what you can do.

It is probably not easy for most of us to hear or think about the reality of what is involved in funerals. However, there can be a satisfaction in leaving your mark on the occasion, and also involving your family beforehand.

tip

If you would like to know more about the practical and emotional aspects of dying, please contact the Helpline and ask about Cancer Council's booklet called, *Facing End of Life: A guide for people dying with cancer, their family and friends*.



Key points

- Getting your affairs in order can be hard, but it may also bring a sense of relief and allow you to focus on treatment and living.
- The rules and regulations that surround the documents you may need to sign vary for each state and territory. Check what is relevant to your local area.
- A will is a legally binding document outlining who receives your assets after your death.
- A substitute decision maker is someone you appoint to make decisions for you, if at some point in the future you are unable to make them for yourself.
- An advance care directive is a legal document that details your wishes for the medical treatment you do or don't want to have.
- An advance care directive can help inform your substitute decision maker to make decisions on your behalf if you no longer have the capacity to do so.
- You can ask your doctor or the hospital to place a copy of the directive on your medical record.
- It may help to access superannuation early or find missing funds to help cover the costs of medical treatment.
- Check if you have insurance attached to your superannuation that may help with medical costs.
- There is help available if you are having trouble paying your utility bills. Ask the hospital social worker or call the Helpline to find out more, as there are different options available in each state and territory.



Caring for someone with advanced cancer

Being a carer can be stressful. Try to look after yourself – give yourself some time out and share your worries and concerns with trusted friends or somebody neutral such as a counsellor or your doctor.

Common reactions

For many carers the most difficult part is thinking about the impact of the diagnosis on the person with cancer. You may be concerned about how they will be affected, if they will be in pain and feel sick, if they will become depressed or withdrawn, or if they will die.

As well as having to manage your own reactions, you may also have to break the news to other family and friends. This can be extremely difficult and exhausting. If you need advice or support there are people you can contact, including your GP, hospital social worker, a palliative care service, a support group, hospital nurses, oncologist or Cancer Council Helpline 13 11 20.

Putting on a brave face

Some carers feel like they have to be strong all the time and don't want to add to the worries of the person with cancer by being 'weak' or by showing their emotions. This is a common reaction. But no one can cope with everything all the time.

Expressing and sharing your feelings can help everyone. If friends and family know how you are coping, they can better understand what support they can provide.

How can I make this better?

You may want to fix things, but you can't change what has happened, and this can be frustrating. It may be the first time you have faced a problem you cannot solve. Feeling powerless and without control is common. Try to focus on what you can do – for example, you can try to:

- listen to the person's concerns
- gather information to help you make informed decisions
- be honest, share your own concerns
- reassure the person with cancer that you love and support them
- look after yourself as much as possible, physically and emotionally. This will help you in your caring role.

Feelings of loss

You may grieve about how things used to be with the person you are caring for, or your loss of time and ability to enjoy life as you used to. You may be starting to grieve the anticipated death of the person you are caring for. Your emotions can go from feeling very caring and protective to feelings of anger and resentment about what you have lost or may lose.

Everyone deals with loss in their own way, but there are things you can do to help. Acknowledging your grief and knowing that it is alright to cry or feel angry helps some people feel more in control.

Most carers find it helps if they feel supported by those around them. Don't be afraid to ask for help or let those close to you know how you are feeling. For more information about coping with loss and grief and how to get support, call the Helpline.

Uncertainty

Many people struggle with uncertainty when the future is unknown. What you had planned for and dreamed about may have changed. Many things might have to be put on hold if you are not sure what is ahead. Try not to make any major changes or big decisions at first. The anxiety will come and go. It can help to learn ways of dealing with it.

- Practise changing your thoughts to focus on what you can do. Remind yourself that you have coped with difficult times before and try thinking about what helped you get through those times.
- Learning to relax may seem impossible at first, however, simple relaxation strategies can make a big difference. Your local community health centre or council may run relaxation, yoga or tai chi classes. Appropriate exercise, adequate sleep and a healthy diet can also help.
- A support group can be helpful. Face-to-face, internet and telephone support groups are available. These are groups of people in a similar situation that meet regularly to share their experiences. There are groups for people with cancer and their carer/s or groups just for carers. See page 74 for details on how to access the different types of support groups.

“ I found the brain tumour support group beneficial. Firstly, to gather knowledge from other people, but then I felt a sense of ‘giving back’ to new members. ” Rosie

- Information helps many people feel they have some control. It can help you to know whether you need to make any changes, and to make decisions based on the facts.
- If at any stage you feel that you are not coping, speak to your doctor or another health professional. They can refer you to a counsellor and prescribe short-term medication if needed.

Depression

Some carers become depressed. This is a natural response to a stressful situation. You will almost certainly find that you have bad days, when nothing seems to go right and your problems feel overwhelming. For many people, these bad days will be relieved by days where, even though things are not perfect, there is still some joy and calmness.

If you find that you are not feeling any pleasure, that you are stressed, irritable or emotional almost all the time, you cannot sleep or have lost your appetite, talk to your doctor. They may be able to show you ways of dealing with these feelings and symptoms, or refer you to a counsellor, psychologist or psychiatrist. They can also recommend medication if it is appropriate for your situation.

People with advanced cancer can also become depressed. If you notice symptoms of depression in the person you are caring for, such as difficulty sleeping, changes in appetite, no longer being able to enjoy the things they usually enjoy, discuss whether they would like to see a counsellor or doctor.

Dealing with the changes

A diagnosis of advanced cancer can change the dynamics and roles within your family, friends or relationship. Changes may only last for a short time or be longer lasting.

How cancer can affect relationships

Cancer can strengthen a relationship or strain it. Try to be open and honest. Before starting a complex or emotional discussion, try to determine if it is a good time to do so. If you begin to feel there is never a good time, perhaps a counsellor or social worker can talk with you about your relationship, illness or your feelings.

You may find yourself thinking about how you will manage if the person with cancer dies. This is natural, but try not to exclude them from everyday events and decisions. If people with cancer are physically able, they often prefer, or even need, to take on daily activities to help maintain their sense of independence. They don't have to, and often don't wish to, feel helpless.

How to find a counsellor

Your GP can refer you to a counsellor, social worker or psychologist at your hospital.

You could also see a private counsellor or psychologist for a fee.

The Better Access initiative allows GPs to refer people to psychologists or social workers for several free sessions.

Your local palliative care service or Helpline can put you in touch with a counsellor who has oncology related experience.

Religious and spiritual beliefs

Some people find that cancer challenges their religious or spiritual beliefs. Others may find it brings new strength and hope.

Often someone with similar faith and values may be able to help you with difficult questions such as, ‘Why is this happening?’ and ‘What have we done to deserve this?’ Some people feel no desire to pursue religion or spirituality at this time. This is a personal decision that only you can make.

Talking about death and dying

When cancer is advanced, one of the first questions family and friends often ask is, “Will they die?” This can be a frightening thought and make it hard to talk about.

The fear can often be mixed with other feelings, such as anger, guilt or sadness, especially if the person with cancer wants to talk but you find it too hard to listen.

Sometimes, knowing the person’s wishes can help you avoid regret or feelings of guilt later on.

Although it can be difficult to discuss, death is an important topic. There can be practical issues to resolve such as place of death as well as emotional ones such as resolving a difference with a close friend or family member.

Cancer Council also has a booklet called *Facing End of Life: A guide for people dying with cancer, their family and friends*.

There may come a time when you are both ready to talk about these issues. But if the person with cancer is not clear what they'd like or is avoiding the conversation you could suggest they talk with someone else. This could be a relative less affected by the diagnosis or a close friend they trust with their thoughts and feelings.

Practical concerns

Work and income

You may need time off work to attend medical appointments or to care for the person with cancer. Explain your situation to your employer. Most employers appreciate honesty and will try to accommodate your needs. Find out your entitlements because you may be eligible for time off. It may be easier for everyone if you have some time off, at least until things settle down and you have a better idea of what is ahead. Some employers will let you take annual leave, long service leave or leave without pay.

If time off is not possible or desirable, talk to friends and family about how they can support you. It may help if you are specific about what you need, for example, transport to appointments, providing company or making meals.

You may be eligible for a carer payment from the government if you provide constant care for the person with cancer (whether or not you work outside the home). Speak to your hospital social worker about the different types and other sources of financial assistance. Cancer Council also has free resources on your rights in regard to care and work.

Accepting help

Not all your family and friends will know how to respond and provide support – some may not know what to do or even avoid contacting you at first. They may want to avoid thinking about their own death or be afraid of saying the wrong thing, so instead say nothing.

This doesn't necessarily mean family and friends don't care; they may just feel unable to deal with the situation. If you like, you could try calling them, explain what is happening or ask them to do a specific task, for example, providing a meal or returning an overdue DVD. This can help someone feel useful or involved and next time they might feel comfortable enough to call you or just drop in. People sometimes need to be told specifically what they can do.

You may find it difficult to accept help, especially if you are used to managing everything. Try to see it as a strategy for getting through a difficult time. You may choose to think of your requests as letting others feel useful, rather than asking for help.

Carers with young children

Carers with younger children will need support. This does not have to be expensive. Call your local council to find out how they can help you. Social and religious groups and

schools can often be good at organising people to cook meals, provide transport and other practical things. Take up offers to help from neighbours and friends.

Emotional and physical strain

Carers need to look after themselves too. Being a carer can be tough, especially over time. Physical wellbeing is often closely tied to emotional wellbeing. Take time to do the things you normally do that help relieve the pressures of the day and give you pleasure. This time-out from caring for a person with cancer strengthens you for the time you devote to them.

Carers often feel like they are on an emotional roller-coaster. Some moments are extreme highs and others extreme lows. On some days, there are times to stop and have a break, but on other days you can feel like you have had enough. At times, you may even find yourself wishing the person would die so you can both have some relief from the disease and its impact.

Providing physical care

Providing physical care is a challenge for many carers. If the person you're looking after needs help to get out of bed, you will need to be taught how to move them safely. Ask the district nurse, doctor or physiotherapist to show you the best way to do this and take care when you do it, as it's easy to injure your back.

If the person you are caring for requires more care than you think you can manage, talk to your doctor. Home nursing services and a palliative care team can provide professional help at home.

LifeCircle also provide support for the carer of someone who would like to be cared for and ultimately die at home. For a listing of available support services, see pages 74–79.

Practical ideas for carers

- Use an answering machine to record messages or ask someone else to return calls if you are tired and don't feel like talking. This avoids having to repeat information for family and friends who like to be kept informed of what is happening.
- Ask someone to take on the role of information provider. Make sure this person has the latest information.
- Group emails, sent regularly, are a great way to let people know what is happening.
- Place a message on the door when it is not a good time for visitors.
- Turn off the phone and have a rest when the person with cancer is resting.
- Talk to people you trust about what is happening. It helps them to understand what you are going through, and helps you release any concerns or stresses you have.
- Make a list of 10 things you like to do and make sure you do one of them each day.
- Take time out. There will be times when you feel exhausted or overwhelmed. This is normal. Take a book and sit outside, go for a walk or go for a drive.
- Try not to do everything yourself – leave some tasks for others to do. It is hard to do everything, no matter how organised you are.
- Be realistic about how much you can do, as doing too much may affect how well you cope. Do what is important and less of what isn't.
- Involve friends and family in the caring.
- Call Cancer Council Helpline **13 11 20** to get in contact someone who has had a similar experience.



Seeking support

There are many things to think of when you find out you have advanced cancer. It is normal to experience a range of emotions and to need time to gather your thoughts and feelings. You and your family or carers will also need to consider practical and financial issues. This chapter gives an overview of different organisations and services that can provide information and help for you and your family.

A-Z of practical and support services

Accommodation

Cancer patients and carers who travel a long way for treatment can often get accommodation at or near the treatment centre. Facilities may be self-contained or shared, and the cost is sometimes subsidised.

- Cancer Council Helpline
13 11 20
- Contact the hospital social worker

Patient Assisted Travel Scheme (PATS) – all states and territories operate a PATS. These schemes provide a subsidy to help with travel, escort and accommodation expenses incurred when rural and remote Australians travel to access specialised health care not available within a specified distance from where they live.

- **1800 899 538**
- www.ruralhealthaustralia.gov.au and search for Patient Assisted Travel Schemes

Carer services

Carers Australia – national body representing Australia’s carers, which can direct you to your state or territory carer association.

- www.carersaustralia.com.au

Counselling and mentoring services

beyondblue – 24-hour telephone counselling service (online or email is also available 7 days a week).

- **1300 22 4636**
- www.beyondblue.org.au

Better Access Initiative – Medicare-subsidised referral to counselling through your GP.

- Visit your GP
- www.health.gov.au/internet/main/publishing.nsf/content/mental-ba-fact-pat

LifeCircle – provides mentoring, telephone support and other support resources for carers.

- **1300 364 673**
- www.lifecircle.org.au

Lifeline – 24-hour crisis support and suicide prevention services.

- **13 11 14**
- www.lifeline.org.au

Mensline Australia – 24-hour telephone and online support, information and referral service to help men with relationship issues.

- **1300 78 99 78**
- www.mensline.org.au

National Association for Loss And Grief – 24-hour telephone support service to help those suffering from loss.

- www.nalag.org.au

National Carer Counselling Program (NCCP) – offers short-term counselling to carers.

- **1800 242 636**

Equipment and aids

Independent Living Centres

Australia – provides information on a range of products and services to help people remain independent and improve their quality of life.

- **1300 885 886**
- www.ilcaustralia.org.au

Financial assistance

Centrelink – offers financial support for people with a long-term illness and for primary carers.

- **13 27 17**
- www.humanservices.gov.au

Funerals

Australian Funeral Directors

Association – provides a listing of funeral directors and estimates of costs. It also has information on pre-paying for a funeral and planning for a funeral.

- **1300 888 188**
- www.afda.org.au

Home help

Support is available for people being cared for at home and their carers. Services vary for each area. Some local councils provide a range of community and in-home services, such as Meals on Wheels or respite care. If you have a palliative care team, they can organise home help for you.

Home nursing

Free home nursing can be organised as part of your palliative care. Private services are also available. If you have private health insurance, your policy may cover home nursing.

- Talk to your palliative care team and/or your private health fund
- Cancer Council Helpline
13 11 20

Hospice care

See palliative care entry below.

Legal advice and information

A solicitor is the best person to ask about any legal matters. If you do not have a solicitor, contact your local state or territory law society for a listing of solicitors in your local area.

Palliative care

Palliative Care Australia – provides information about palliative care services and facilities, and can link you to your local palliative care office.

- www.palliativecare.org.au

Care Search – online palliative care resources, services and evidence for patients, carers and families.

- www.caresearch.com.au

Australian Government Department of Health – responsible for cancer and palliative care information.

- www.health.gov.au

Pastoral care

Most large hospitals have a pastoral worker who can talk to you about practical and spiritual concerns (from all religious and non-religious viewpoints).

- Contact your hospital

Respite care

Commonwealth Respite and Carelink Centres – can organise respite care for you, that is, when a patient is looked after by someone other than their usual carer. This gives their regular carer a break and time to attend to their own personal needs. Respite care can be for a few hours, overnight or for blocks of time.

- **1800 052 222** (business hours)
- www.health.gov.au
- Your palliative care team or social worker can advise

Social worker

A hospital social worker offers a range of services for you and your family, such as counselling and debriefing. They can provide a link between you and the hospital system, and can help if you have any problems at the hospital.

- Contact your hospital or local community health centre

“I found that my support group was a useful, safe place to express my emotions and experiences without having to censor myself to protect the feelings of other people.” Jann

Support groups

Many people find joining a support group helpful. Support groups allow people with cancer to talk about their experiences, hopes and fears in a non-judgmental, caring environment.

Face-to-face groups – meeting with others who understand what it is like to have cancer can be helpful. You may be reluctant to share your story or listen to other people's, but most people find they benefit from the close bonds formed with other members.

- Cancer Council Helpline **13 11 20**
- Contact your hospital social worker to see if they run any support groups

Telephone support groups – if getting together with others in person isn't possible, you can join a Cancer Council telephone support group. There are groups for advanced cancer, carers and different cancer types.

- Cancer Council Helpline **13 11 20**

Online discussion forms – people can connect with each other at any time, ask or answer questions or write a blog of their experiences.

- www.cancerconnections.com.au



Useful websites

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

Australian

Cancer organisations

Cancer Council Australia.....	www.cancer.org.au
Breast Cancer Network Australia	www.bcna.org.au
Cancer Australia.....	http://canceraustralia.gov.au
Peter MacCallum Cancer Centre.....	www.petermac.org
Radiation Oncology	
Targeting Cancer	www.targetingcancer.com.au

Australian Government agencies

Department of Health	www.health.gov.au
Department of Human Services	www.humanservices.gov.au
Department of Social Services	www.dss.gov.au
Ehospice.....	www.ehospice.com
HealthInsite.....	www.healthinsite.gov.au
Therapeutic Goods Administration	www.tga.gov.au

Counselling services

beyondblue.....	www.beyondblue.org.au
Canteen	www.canteen.org.au
Caresearch	www.caresearch.com.au
Carers Australia	www.carersaustralia.com.au
Lifeline	www.lifeline.org.au

Specific cancer-type organisations

Gynaecological

Cancer Support www.gynaecancersupport.org.au

Leukaemia Foundation www.leukaemia.org.au

Lung Foundation Australia www.lungfoundation.com.au

Melanoma Patients Australia www.melanomapatients.org.au

National Breast and

Ovarian Cancer Centre www.canceraustralia.gov.au

National Indigenous Cancer Network www.nican.org.au

Ovarian Cancer Australia www.ovariancancer.net.au

Prostate Cancer Foundation of Australia www.prostate.org.au

International

American Cancer Society www.cancer.org

Macmillan Cancer Support www.macmillan.org.uk

Medline Plus – Alternative Therapies

..... www.nlm.nih.gov/medlineplus/canceralternativetherapies.html

Memorial Sloan-Kettering

Cancer Center www.mskcc.com

National Cancer Institute www.cancer.gov

National Center for Complementary

and Alternative Medicine <http://nccam.nih.gov>



Question checklist

You may find this checklist helpful when thinking about the questions you want to ask your doctor about advanced cancer and treatment. If your doctor gives you answers that you don't understand, ask for clarification.

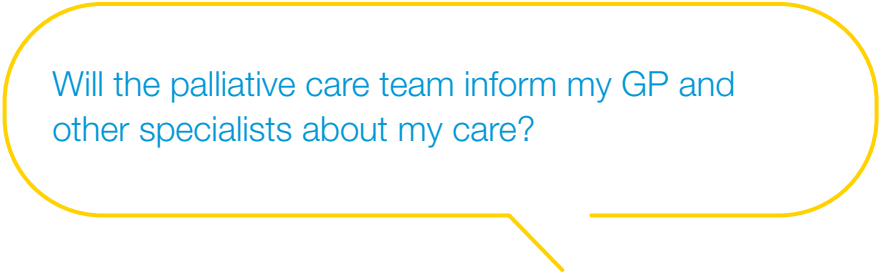
Practical questions

- What type of cancer do I have and where has it spread?
- How extensive is the cancer?
- What is my prognosis? How long am I likely to live?

Treatment questions

- What treatment do you recommend?
- Are there other treatment choices for me? If not, why not?
- Are there any clinical trials of new treatments?
- Are there any complementary or alternative therapies that might help me?
- What treatment do you suggest for any pain or discomfort?
- What are the risks and possible side effects of any suggested treatments?
- What are the risks and possible outcomes if I choose to have no treatment?

What are the risks and possible side effects of any suggested treatments?



Will the palliative care team inform my GP and other specialists about my care?

Questions for your health professionals

- Which health professional should I contact first if I am unwell or if there is an emergency?
- Can I access palliative care?
- Does the palliative care team inform my GP and other specialists about my care?
- How much will treatment or palliative care cost?
- How frequently will I have check-ups?
- Can you help me explain my prognosis to my family?
- What can I expect to happen in the future?

References

1. Cancer Council Victoria 2008. *When Cancer Won't go Away: for people whose cancer has advanced*. Melbourne: Cancer Council Victoria.
2. Cancer Council Victoria 2008. *When Cancer Won't go Away: for carers of people whose cancer has advanced*. Melbourne: Cancer Council Victoria.
3. Cancer Council NSW 2010. *Living with Advanced Cancer: a guide for people with cancer, their families and friends*. Sydney: Cancer Council NSW.
4. Cancer Council NSW 2013. *Understanding Palliative Care*. Sydney: Cancer Council NSW.
5. A National Framework for Advance Care Directives, September 2011, AHMAC www.ahmac.gov.au/cms_documents/AdvanceCareDirectives2011.



Glossary

You may come across new terms when reading this booklet or talking to health professionals. You can check the meaning of other health-related words at www.cancercouncil.com.au/words or www.cancervic.org.au/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 decisions. It provides a legal means for a competent adult to appoint a substitute decision maker and/or record their choices for future health and personal care.

advanced cancer

Cancer that has spread to other parts of the body or moved away from the original site (metastasised) and is less likely to be cured.

alternative therapies

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

anaesthetic

A drug that stops a person feeling pain during a medical

procedure. A local anaesthetic numbs part of the body; a general anaesthetic causes a person to lose consciousness for a period of time.

analgesic

A drug or natural remedy used to relieve pain without causing a loss of consciousness.

carer

A person who provides physical and/or emotional support to someone who is ill or living with a disability.

cells

The basic building blocks of the body. A human is made of billions of cells, which are adapted for different functions.

chemotherapy

The use of cytotoxic drugs to treat cancer by killing cancer cells or slowing their growth.

Chemotherapy can also be used to reduce the size of the cancer and help lessen pain.

chronic disease

An illness or disease that is long lasting and may change the way a person lives their life.

complementary therapies

Supportive treatments that are used in conjunction with conventional treatment. They may improve wellbeing and quality of life and help people cope with side effects of cancer.

cytotoxic

A substance that is toxic to cells.

enduring guardian

A person who has the power to make medical decisions for a person who has lost the capacity to make their own decisions.

euthanasia

The act or practice of deliberately ending the life of a person suffering from a terminal illness or incurable condition. It is illegal in all states and territories in Australia.

inpatient

A patient who is accommodated in a hospital while they receive treatment.

lymphatic system

A network of tissues, capillaries, vessels, ducts and nodes that removes excess fluid from tissues, absorbs fatty acids and transports fat, and produces immune cells.

malignant

Malignant cells are those that can spread to other parts of the body (metastasise) and can invade other tissue and eventually cause death if they cannot be treated. Cancer is malignant.

metastasis

A cancer that has spread from another part of the body. Also known as secondary cancer. The plural form of metastasis is metastases.

morphine

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 different treatments and care. A palliative care team offers multidisciplinary care.

oncologist

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

osteoporosis

When the bones become brittle as a result of the loss of calcium.

outpatient

A patient who is not hospitalised overnight but who visits a hospital, clinic, or associated facility for diagnosis or treatment.

palliative care

The holistic care of people with a life-limiting illness, their families and carers. It aims to improve

quality of life by addressing physical, emotional, spiritual, social and practical needs. It is not just for people who are about to die, although end-of-life care is a part of palliative care.

palliative care unit

A place that provides comprehensive care for people with a limited prognosis. This includes inpatient medical care, respite care and end-of-life care for people who are unable 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 of cancer.

personalised medicine

The application of the right treatment for the right patient, at the right dose, and at the right time. Also known as individualised treatment.

power of attorney

The ability for a person to act on behalf of another on financial and legal matters.

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 likely outcome of someone's disease.

radiotherapy

The use of radiation, usually x-rays or gamma rays, to kill cancer cells or injure them so that they cannot grow and multiply. Sometimes radiotherapy is used to control pain.

recurrent cancer

A cancer that grows from cells of the primary cancer that have resisted treatment or cancer that has spread in the body.

relapse

The return of a disease after a period of improvement.

respite care

Care given to a sick person to give their regular carer a break. Respite care can be given in the home, at hospital or in a palliative care unit.

resuscitation

The process of reviving someone who appears to be dead, for example by heart massage or artificial respiration.

second opinion

Talking to another doctor to consider other treatments, confirm a diagnosis or recommended course of treatment.

secondary cancer

Cancer that has spread from the original site to another part of the body. Also called a metastasis.

tumour

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



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 Pink Ribbon Day, 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 Helpline 13 11 20

Cancer Council Helpline is a telephone information service provided by Cancer Council NSW for people affected by cancer.

For the cost of a local call (except from mobiles), you can talk about any concerns confidentially with oncology health professionals. Helpline consultants can send you information and put you in touch with services in your area. If you need information in a language other than English, an interpreting service is available.

You can call the Helpline, Monday to Friday, 9am to 5pm.

If you have difficulty communicating over the phone, contact the National Relay Service (www.relayservice.com.au) to help you communicate with a Cancer Council Helpline consultant.

For more information, go to www.cancercouncil.com.au.

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Care
Australia



Cancer Council
Helpline

13 11 20

For support and information on cancer and cancer-related issues, call Cancer Council Helpline. This is a confidential service.

For further information and details please visit our website: **www.cancercouncil.com.au**