

Living with advanced cancer

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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, 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.

What happens now?

You will need time to deal with the news 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](#) section.

Who else can I talk to?

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 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. You may 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.

What treatments are available to me?

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 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](#) section.

Who is in charge of my treatment?

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.

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

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 the [Managing symptoms](#) section.

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 e.g. some hormonal treatments affect people's emotions (sometimes including their anger levels). And all the other possible changes to work, care, finances, symptoms may themselves result in emotional changes.

Palliative care

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.

Am I going to die?

Death can be one of the first things 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 [13 11 20](tel:131120) for a free copy of [*Facing End of Life: A guide for people dying with cancer, their family and friends.*](#)

What hope is there?

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.

Emotional impact

When you are first told, or come to realise, 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 different, possibly stronger reactions than when you heard for the first time 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.

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 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 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.

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 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 the 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 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 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](tel:1300224636)
www.beyondblue.org.au

Black Dog Institute

www.blackdoginstitute.org.au

Lifeline 24-hour Telephone Crisis Support

[13 11 14](tel:131114)
www.lifeline.org.au

Being realistic

Some people believe the attitude of the person with cancer can influence the outcome of the disease. While it can help to be optimistic it 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.

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 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 away²⁸ or stop contacting you. They may take time to adjust to the²⁹ fact 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 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 the [Seeking support](#) article.

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.

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 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.

However most partners 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 [13 11 20](tel:131120) 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 their 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.

- 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

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.

- 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.

Children

Children need explanations 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 something is wrong. They may notice changes at home such as your distress or an increase in visitors.

Assure children 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 there will always be someone to care for them.

- 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.
- 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 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.

- 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 website www.nowwhat.org.au.

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 things are the same as always. Having to rely on your adult children more and more may make you feel guilty.

- 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.



For more information and tips on discussing cancer with children, call Cancer Council [13 11 20](tel:131120) for a free copy of the book [*Talking to Kids About Cancer*](#).

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.

- 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 [13 11 20](tel:131120).
- 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 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](tel:131114) for free, confidential telephone counselling at any time of the day or night.

Treatment for advanced cancer

Some people believe 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](#).

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 Cancer Council [13 11 20](#). A list of [reliable websites](#) can also be found here.

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

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 two to three 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 e.g. removing the testicles to reduce testosterone levels and slow the growth of prostate cancer.

Radiotherapy

Radiotherapy uses radiation to kill cancer cells or injure them so 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 cause 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 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.

Palliative care workers:

- 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 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 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 is 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 Cancer Council [13 11 20](tel:131120) for more information about palliative care, how to access it and how it can benefit you.

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 myagedcare.gov.au or call [1800 200 422](tel:1800200422).

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 they've tried every available option. For many people complementary or alternative therapies give them a sense of control.

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 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 e.g. 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 Cancer Council [13 11 20](tel:131120) for more information on complementary therapies, meditation or relaxation or for a free copy of the book [Understanding complementary therapies](#).

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 e.g. 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 it has failed you. You may hope that an alternative therapy offers a cure.

However, some alternative therapies can be harmful e.g. 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.

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.

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.

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.

It is important 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.

- Prepare a list of questions before your appointments and let your doctor know early on that you have 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 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.

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
- treating the cause of the pain with chemotherapy, radiotherapy or surgery.

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.

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.

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.

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 [13 11 20](tel:131120) 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.
- Constipation—this can be prevented by taking laxatives regularly.

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.

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 e.g. 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.

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.

- Eat small meals or snacks regularly. Hunger or an empty stomach can make nausea worse.
- Try eating cold foods such as sandwiches, dry biscuits, stewed fruit, jelly or yogurt.
- 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

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. Read Cancer Council's [Nutrition and Cancer](#) booklet for tips on dealing with nausea and lack of appetite. Call Cancer Council [13 11 20](tel:131120) for a copy.

- 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 e.g. 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

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.

- 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 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

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.

- 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.

Clinical trials

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 Cancer Council [13 11 20](#). You can also find trials on the website www.australiancancertrials.gov.au.

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 certificates²⁸
- bank and credit card information
- ²⁸ 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.

Having capacity to sign a legal document

When you make a will, appoint a substitute decision maker²⁸ 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 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.

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 substitute⁵⁹ decision maker²⁹

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, should²⁸

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 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 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.

What to do with your advance care directive

Keep a copy of your advance care directive for yourself and 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.

For further information visit advancecaresdirectives.sa.gov.au and advancecareplanning.org.au.

[Advance Care Planning Australia](http://AdvanceCarePlanningAustralia.com) also has their information available in 15 other languages which can be accessed via their home page.

Accessing superannuation

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 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](tel:131020).

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 Cancer Council [13 11 20](#) for these free resources.

Planning for your funeral

You may wish to plan your funeral or memorial service so 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.

If you would like to know more about the practical and emotional aspects of dying, please contact Cancer Council [13 11 20](#) and ask about Cancer Council’s booklet called [Facing End of Life](#).

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 section 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 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.	Country Health SA 1800 188 115 www.countryhealthsa.sa.gov.au/PATS

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 seven days a week).

[1300 22 4636](tel:1300224636)
www.beyondblue.org.au

Better Access initiative –

Medicare-subsidised referral to counselling through your GP.

Visit your GP

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

[1300 364 673](tel:1300364673)
www.lifecircle.org.au

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

[13 11 14](tel:131114)
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](tel:1300789978)
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](tel:1800242636)

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.

Cancer Council [13 11 20](http://www.cancer.org.au)

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 [13 11 20](http://www.cancer.org.au)

Hospice care

See palliative care entry

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. [Click here](#) for more information.

Cancer Council [13 11 20](#)

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

Palliative Care South Australia

www.pallcare.asn.au
(08) 8271 1643

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 or religious organisation

Respite care

My Aged Care – can organise respite care for carers (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.

www.myagedcare.gov.au
[1800 200 422](tel:1800200422)

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

Cancer Council [13 11 20](tel:131120)

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 find they benefit from the close bonds formed with other members.

Cancer Council [13 11 20](tel:131120)

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 [13 11 20](tel:131120)

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

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
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	
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
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?
- What can I expect to happen?
- How long am I likely to live?

Treatment questions

- What treatment might be available?
- Are there any clinical trials suitable for me?
- Are there any complementary therapies that might help me?
- Will I have any pain or discomfort?
- What will happen if I choose to have no treatment?
- What are the risks and possible side effects of any suggested treatments?

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?

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