



Understanding Palliative Care

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

A large yellow shape, resembling a stylized figure or a large drop, occupies the lower half of the page. A purple circle is attached to the right side of this shape. A thin orange line extends from the bottom of the purple circle, curving down and then left to point towards the helpline information.

Treatment

Cancer Council Helpline

13 11 20

www.cancercouncil.com.au

Understanding Palliative Care

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

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Note to reader

Always consult your doctor before beginning any health treatment. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for your doctor's or other health professional's advice. However, you may wish to discuss issues raised in this booklet with them. All care is taken to ensure that the information in this booklet is accurate at the time of publication.

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, your family and carers understand more about receiving palliative care. Although palliative care is for people with any advanced, life-limiting illness, this booklet has been written specifically for people affected by cancer.

The aim of palliative care is to enhance your quality of life and help you maintain your independence for as long as possible. To achieve this, health professionals from different fields of care work together as a multidisciplinary team to organise access to services that meet your physical, emotional, spiritual and practical needs.

The way palliative care is managed differs across Australia due to availability of services. It is also tailored to an individual's unique needs. It can be coordinated by your general practitioner (GP) or community nurse, or you may be referred to a specialist health professional or team. Care may be provided in or out of your home. Your GP or palliative care team will talk to you and your carers about your case.

The question checklist and glossary of medical terms at the back of this booklet may help in your discussions. You can also call Cancer Council Helpline 13 11 20 for more information.

The information in this booklet was developed with help from Palliative Care Australia, medical experts and people using palliative care services.



Contents

When cancer is advanced	4
--------------------------------------	----------

Key questions	6
----------------------------	----------

What is palliative care?.....	6
-------------------------------	---

Does it mean end-of-life care?.....	7
-------------------------------------	---

Does it prolong life unnecessarily?.....	7
--	---

Is it the same as euthanasia?	8
-------------------------------------	---

How can palliative care help?	8
-------------------------------------	---

When can I access palliative care?	10
--	----

Who will organise my care?.....	10
---------------------------------	----

Where do I receive palliative care?.....	11
--	----

Will I still have medical treatment?	12
--	----

Will I be told my prognosis?	13
------------------------------------	----

Will I lose my independence?.....	14
-----------------------------------	----

Do I have to pay for palliative care?	14
---	----

Can I use any complementary therapies?	16
--	----

What is advance care planning?	17
--------------------------------------	----

Which health professionals will I see?	18
---	-----------

Information for carers	26
-------------------------------------	-----------

Respite care	26
--------------------	----

Counselling and mentoring	28
---------------------------------	----

Palliative care for young people.....	29
--	-----------

Seeking support	31
------------------------------	-----------

Talk to someone who's been there.....	32
---------------------------------------	----

Useful organisations and resources	33
Financial support.....	34
Useful websites	36
Question checklist.....	37
Glossary	38
Notes	42
How you can help.....	44



When cancer is advanced

There are many types of cancer and they all develop differently:

- Some cancers grow slowly, while others may advance rapidly.
- Cancer cells may be predictable in their behaviour or erratic and unpredictable.
- Certain types of cancer respond well to treatment in most people, while other types are more difficult to treat. Although many early cancers can be treated successfully, some people now living with cancer will die of the disease.

Advanced cancer is a term used to describe cancer that has spread and is unlikely to be cured. It may refer to a primary or secondary (metastatic) cancer.

Primary cancer refers to the first mass of tumour cells that have divided and multiplied uncontrollably in an organ or tissue. The tumour is confined to its original site, such as the bowel or lung.

Secondary cancer is when tumour cells from the primary cancer site break off and spread to other parts of the body by moving through the blood or lymphatic system. If cancer spreads, it is common for it to move into the liver, bones or brain. This spread is also known as metastasis.

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

When cancer is advanced, different organs in the body can stop working properly. If the liver is involved, the levels of chemicals in the body can cause problems. Tumours can grow and press on vital organs, affecting the way the organs function and causing discomfort or pain.

Even though medical interventions may not be able to cure the cancer, some treatments may still be able to slow its growth or spread. Palliative medicine can also help manage pain or other symptoms associated with cancer and its spread. It can reduce side effects from cancer treatments. See page 12 for information about medical treatment used in palliative care.

As well as organising medical treatment, the palliative care team can provide services that care for your emotional, physical, practical and spiritual needs. This team approach can help to enhance the quality of life of people with cancer and their families, whatever stage the advanced cancer is at.

For more information about advanced cancer, call Cancer Council Helpline 13 11 20.

“ 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



Key questions

Q: What is palliative care?

A: Palliative care allows people with advanced cancer to maintain their quality of life in a way that is meaningful to them. It also provides support to families and carers.

The role of palliative care is to:

- help you achieve the best quality of life that you can for as long as possible
- make sure your physical, practical, emotional and spiritual needs are catered for
- help you feel in control of your situation and make decisions about your treatment and ongoing care
- make the time you have as valuable as can be for you and your family – not prolong or shorten life.

Palliative care incorporates a range of services offered by medical, nursing and allied health professionals, as well as volunteers and carers. This is called a multidisciplinary team (MDT) approach. See pages 18–23.

You will have appointments with your health professionals so they can monitor you and adjust your treatment and care. This helps to prevent or resolve any issues that may arise because of the cancer.

“Working in palliative care allows us, as nurses, to provide patients with the most compassionate care possible, at a time when they may be quite vulnerable.”

Nurse

Q: Does it mean end-of-life care?

A: Palliative care is about living for as long as possible in the most satisfying way you can, within the limits of your illness. It's not simply about dying.

While some people may only use palliative care services for a few weeks or months, the number of people receiving care for several years is increasing. Because improved treatments can help stop the spread of cancer and relieve side effects, cancer may be considered a chronic (long-lasting) disease. You can have palliative care while you are having active treatment.

One reason that some people don't access palliative care services early – or at all – is because they have the fear or misconception that by doing so, it will mean they have given up hope or are going to die soon.

The reality is that some people do die from cancer. As people draw closer to death, the end-of-life care aspect of palliative care becomes important.

Q: Does it prolong life unnecessarily?

A: Palliative care does not try to prolong life. Instead, the health care team provides multidisciplinary care to enhance people's quality of life. This may include pain management.

Some studies show that controlling symptoms, such as pain, can lead to people feeling better and living longer.^(1,2)

Q: Is it the same as euthanasia?

A: Palliative care and euthanasia are not the same thing. Euthanasia is when a person's life is deliberately ended so that they avoid suffering from an incurable condition or illness. This is illegal in every state and territory in Australia.

Palliative care is about coordinating medical and support services so that someone with a life-limiting illness is made as comfortable as possible. Palliative care can help a person maintain quality of life, but it does not aim to lengthen or shorten life.

👏 Take care of all your end-of-life jobs and then try to live life at the optimum level you are capable of. 🗣️ *Aaron*

Q: How can palliative care help?

A: The palliative care team is there to help make life easier for you, your family and carers. Besides the specific medical and support services that palliative care offers, which are discussed in this booklet, there are many general benefits:

- If you're home, the team helps to keep you out of hospital by regularly checking on you, either by phone or house visits.
- Your care is coordinated by someone, usually a community or palliative care nurse, who communicates with the team on your behalf.
- Communication with the palliative care team may help reduce feelings of isolation or not being able to cope, and it may help your family look after you.

- Learning how to make adjustments around the house can reduce stress for both you and your family.
- The team can help you plan for the future, such as the type of care you may need and where you will receive the care.
- Many palliative care services offer a free 24-hour hotline to offer support and information after hours and on weekends.

Another aspect of palliative care is giving you and your family emotional support. Your team can talk to you about any needs or desires that you may have, and can help you achieve your goals. In some cases, this emotional support is particularly important for people who are close to dying. Some people have specific end-of-life wishes; others seek to make the most out of each day. You might focus your energies on short-term plans, enjoying time with friends and family, and reflecting on the joys in your life.

As well as the general emotional support provided to you, a social worker or counsellor can help you and your family deal with loss and grief. Your family may be eligible for bereavement counselling. The palliative care team will direct you or your family members to bereavement information and resources.

A report by the NSW Ministry of Health found that, of the 13,000 people in NSW who die of cancer each year, two-thirds receive specialist palliative care. About 10% receive this care in the last year of their life.⁽³⁾



Q: When can I access palliative care?

A: It's advisable to access palliative care as early as possible, even if it's just to make contact with the palliative care team.

You can find out what the different team members do and which services might be relevant now or in the future. Being able to deal with problems earlier rather than later will help reduce stress on you and your family.

You can have palliative care for as long as you need: you may live comfortably for months or years; or the cancer may advance rapidly so that your care is focused on end-of-life needs soon after your referral. Whatever stage you're at, your team will continually assess your changing needs and will adjust your care as required.

Q: Who will organise my care?

A: The way you receive palliative care depends on your situation:

- Your primary health care provider, such as a GP or a community nurse, may coordinate your palliative care.
- If your needs are complex and beyond the scope of your primary health care providers, you may be referred to a specialist palliative care team. Your GP and community nurse will continue to be involved.

To access the specialist team, speak to your community nurse or GP for a referral.

Once you've been referred, the team will always consult your GP or nurse about your care and treatment. It's also important for your key family members or carers to be involved in these discussions, as they often will be providing most of your ongoing, day-to-day care.

Q: Where do I receive palliative care?

A: You can have palliative care in different settings depending on your situation, where you live and the support available to you (e.g. if you have family or friends who can help). Care can be provided at home or in an aged care or residential care facility, palliative care units, hospitals or hostels. Patients can move between these settings if their needs change.

If you are cared for at home, you (and anyone who cares for you) can be supported by community palliative care services. Many people prefer to receive care at home. However, some people feel that they will be too much of a burden on their family. An important role for the palliative care team is to assess the best place for your care. They will consider your home environment and your support networks before discussing the options with you, your family and carers.

tip

If you are admitted to a public hospital, palliative care unit or other facility and you have private health insurance, check with your health fund about what is covered.

Finding hope

Sometimes people don't access palliative care services because they hope that a cure will be found for their cancer. You may also find that your primary health care provider, such as your GP, is reluctant to talk about palliative care because they don't want you to think that they have given up hope.

However, you can still benefit from palliative care without giving up hope. People can have palliative care for several months or years and continue

to enjoy many aspects of their life. You may take pleasure in various activities, such as doing small projects, talking to friends, or exploring new hobbies. You may find that a creative activity, such as writing or art, allows you to record your feelings and helps you to make sense of your changed situation.

As your disease progresses, you may hope to live as comfortably as you can for as long as possible.

Q: Will I still have medical treatment?

- A:** Medical treatment for palliative patients is an important part of care. It aims to manage the physical and emotional symptoms of cancer without trying to cure the disease. Some examples of palliative medical treatment are:
- radiotherapy to reduce pain if cancer has spread to the bones
 - chemotherapy to stop the cancer growing into other organs
 - medication to relieve constipation, nausea or pain
 - medication for depression, anxiety or insomnia.

Call Cancer Council Helpline for more information on medical treatment for advanced cancer, and detailed information about cancer pain and pain medication, including opioids such as morphine.

Q: Will I be told my prognosis?

A: Some people want to know whether and when they will die from cancer; others don't wish to know. If you are offered palliative care, it does usually mean that at some stage you may die because of the cancer.

However, no-one can tell you exactly when you are going to die. Your doctors may be able to give a general indication of your life expectancy, based on an average patient, but everyone is unique and responds differently to different kinds of medical, social, spiritual and emotional care.

Dealing with death is difficult and confronting for most people and their families, whatever their cultural background or religious beliefs. Talking over any fears, worries, guilt or other emotions you are experiencing can help you come to terms with your condition.

Consider sharing your thoughts with your loved ones, or speak to a trained counsellor, psychologist or spiritual adviser. Cancer Council has information about coping with your emotions – call the Helpline on 13 11 20 or visit your local Cancer Council website.

Q: Will I lose my independence?

A: The palliative care team gives you choices to help you remain independent for as long as possible. An example is getting a ramp installed at home so you don't have to use the steps. The team respects your wishes if you don't want to take up their suggestions.

Q: Do I have to pay for palliative care?

A: The Federal, State and Territory Governments fund core palliative care services so that they are free in the public health system, whether you receive care at home or in a public setting. However, sometimes you may need to contribute to the costs of care. Some examples are:

- hiring specialised equipment for use at home
- paying for your own nursing staff if you elect to stay at home and require 24-hour assistance
- paying for complementary therapies, such as massage therapy
- paying an excess if you have health insurance that covers palliative care and you go to a private hospital
- accessing respite services that may charge a small fee
- paying a dietitian's fee that isn't covered by a Medicare rebate.



Cancer Council has practical information on health care rights for people with cancer. It covers topics such as specialist care, second opinions, privacy, finances, insurance and advanced cancer issues. Call the Helpline for a free booklet or fact sheets.



Jackie's story

Jackie's mother Diana had advanced lung cancer and the family wanted her to be cared for at home. As her mother's primary carer, Jackie was supported by the local palliative care team.

A nurse coordinated Diana's discharge from hospital and organised for Jackie to hire a hospital bed and purchase other equipment, such as bed pans, for her mother.

A physiotherapist from the hospital taught Jackie how to use the bed and equipment, and showed her ways to lift and move her mother safely. A palliative care specialist prescribed medication and made sure Jackie knew how to administer it to Diana.

As Diana needed round-the-clock nursing care, Jackie paid for agency nurses to attend on a 24-hour roster. The palliative care team visited every day and

were available on the phone whenever Jackie had questions.

After Diana died, surrounded by relatives and in familiar surroundings, Jackie received bereavement counselling through the hospital to help her come to terms with her mother's illness and death.

Q: Can I use any complementary therapies?

A: If you have been referred to palliative care services because your cancer is advanced, you may wonder whether there are any complementary or alternative therapies that you should try in case they offer some chance of a cure.

The decision to use complementary or alternative therapies is yours to make, but there is no scientific evidence to prove that such therapies will provide a cure.

However, some complementary therapies may help you enhance your general wellbeing and cope better with pain and other symptoms you have, such as insomnia, anxiety or digestive problems. Complementary therapies that may help include:

- acupuncture
- massage
- aromatherapy
- relaxation
- meditation
- herbal medicine
- nutrition
- art and music therapy.

“ I found it difficult to relax. Regular aromatherapy massage changed that. It also helped me to maintain mobility and it relieved discomfort and tightness. ” Jo

While some cancer treatment centres offer therapies as part of their services, you may have to go to a private practitioner. Self-help CDs or DVDs can also guide you through different kinds of techniques.

Let your doctor know about any complementary therapies you want to use. This is important, as some therapies may not be appropriate, depending on your conventional treatment and state of health. For example, some herbs or nutritional supplements may interact with your medication, resulting in harmful side effects.

Q: What is advance care planning?

A: You may decide to outline your wishes for your future medical care. This is called advance care planning, and it can be organised at any stage, whether you are healthy or ill. Outlining your wishes and updating your affairs doesn't mean you have given up or are going to die soon – most people review their wishes from time to time.

Each state or territory has different laws about advance care planning. Talk to a social worker or call 13 11 20 for more information.



Which health professionals will I see?

Your palliative care team will be made up of medical, nursing and allied health workers who offer a range of services to assist you, your family and carers throughout your illness, whether you are being cared for at home or in another setting.

Some roles overlap and assistance varies across Australia, but the most common health professionals are listed in this chapter. You won't necessarily see all these people – your family doctor, nurse or palliative care specialist can help you work out which services will benefit you most.

General practitioner (GP) or family doctor

- continues to see you for day-to-day health care issues if you are being cared for at home (and may be able to make home visits)
- liaises with your nurse and/or palliative care specialist about the coordination of your ongoing care
- refers you to a palliative care specialist or organises your admission to hospital or a hospice if your circumstances change
- may be able to assist your family and carers with grief issues, and can refer you to counselling if necessary.

Nurse

- coordinates other health professionals and works out what care you need, including home nursing or personal care assistance
- makes sure you have access to medicines and other treatments for pain and symptom relief, and talks to you about how to take your medication
- helps you with practical things, such as knowing what to expect and how to pace your day.

Palliative care specialist or physician

- prescribes or recommends treatment for pain, nausea, constipation, anxiety, depression or shortness of breath, and any other symptoms you may have
- may be able to visit you in your home, as well as in hospital, a residential care facility or hospice
- communicates with and advises the oncologist and your GP so your treatment is well coordinated
- may refer you and your family to a grief counsellor or a psychologist
- assists with decision-making about care choices.

Health professionals in the team

The people in the palliative care team will work together to help meet your physical and emotional needs, and provide support to your family and carers.



Counsellor or psychologist

- encourages you to talk about any fears, worries or conflicting emotions you may be feeling
- helps you to work through feelings of loss or grief
- assists you and your partner with relationship issues
- helps you resolve problems so that you can find more pleasure in your life
- teaches you strategies to handle anxiety
- may show you meditation or relaxation exercises to help ease physical and emotional pain
- helps you to communicate better with your family
- provides bereavement care to your family and carers.

Pastoral carer or spiritual adviser

- supports you in talking about any spiritual matters on your mind
- reflects with you about your life and helps you search for its meaning, if appropriate
- helps you to feel hopeful and develop ways to enjoy your life despite your illness
- may organise special prayer services for you
- connects you with other members of your faith
- may discuss emotional issues, as many are trained counsellors.



If you have certain cultural or religious beliefs about death and bereavement, or certain family customs, talk to your palliative care team early on. Your customs can often be integrated into your palliative care.

Social worker

- provides counselling and emotional support to you and your family, including working through feelings of loss and grief
- assists with communication within the family, including any relationship issues
- discusses ways of coping and how to emotionally support your children or grandchildren
- provides information and referrals for legal matters, home respite care, meal services, parking schemes, personal alarms, laundry services, and aged care services
- helps you access financial support you're eligible for.

Occupational therapist or physiotherapist

- helps make the physical aspects of your daily activities easier, such as walking, bathing, and getting into and out of bed and chairs safely
- organises equipment hire or modifications to your house for a safer, more accessible environment
- teaches carers and family the best ways to move you or help you sit and stand
- assists with pain relief techniques, such as positioning your body appropriately, using hot and cold packs, and stimulating certain nerves in your body
- advises you on physical aids to improve your mobility, such as a walking frame or a device to help you put on your socks
- shows you how to exercise to reduce pain and stiffness, and to increase mobility and energy
- may also work with a massage therapist for relief of stiff and sore muscles or swelling.

Pharmacist

- gives you access to prescription and over-the-counter medication
- provides information about how to take medication, and any side effects or interactions with other drugs
- communicates with the prescribing doctor, if necessary
- helps you with symptom management so you can achieve the best possible quality of life
- assists you or your carer with keeping track of medications, including the costs on the Pharmaceutical Benefits Scheme (PBS).

Dietitian

- works out the best eating plan for you and your family
- helps you choose appropriate food and nutritional supplements
- tries to resolve any digestive issues, such as poor appetite, nausea or constipation
- assesses and helps you deal with eating and swallowing problems.

If your GP refers you to a dietitian in private practice as part of your Enhanced Primary Care (EPC) plan, you are eligible for a Medicare rebate. To find out more about how dietitians can help you, visit the Dietitians Association of Australia website, www.daa.asn.au.

tip

Ask your palliative care team if they have a 24-hour telephone service. You can keep the number by the phone if any unexpected problems come up.

Volunteers

Volunteers can be an important part of a palliative care team. They carry out a range of support activities, such as helping directly with your care, taking you shopping or to appointments, giving your carer a break, minding children, doing basic jobs around the house, or simply providing companionship and a non-judgmental presence.

Some specialist palliative care units include volunteers who become part of the team. Usually volunteers only help out with specific, agreed tasks.

Despite being unpaid, volunteers are bound by the same professional standards as paid members of the team. They go through a thorough selection process that includes training and criminal history checks. If you think a volunteer would be of help, talk to your nurse who can refer you to the coordinator of volunteer services in your area.

You could also ask someone you know to volunteer to help you. Although you may feel embarrassed about asking for help, you will probably find that many people want to do something for you. If someone offers to help, give them a particular task so that they don't have to guess what might be useful for you.

“ I enjoy helping people out, whether it's stringing up Christmas lights or helping record someone's life story. It's incredibly rewarding and a pleasure to help. ” Cheryl



Brian's story

Janine Sayers' husband received palliative care at home for seven months during his illness. The following story highlights how palliative care services can benefit someone with cancer, their family and carers. Availability of services does vary from area to area. Ask your GP or call Cancer Council Helpline 13 11 20 to find out what you can access. For source information, see the inside front cover.

“Brian was diagnosed with a brain tumour when he was 41. Until then, he had been extremely fit and healthy. We had five beautiful children and ran our own business. We had no idea that our lives were about to be forever altered.

Brian was operated on five days following diagnosis, and some weeks later began a course of radiation and chemotherapy. Not long after this, he required further surgery, allowing him some respite for a few months. But then the nurses suggested we call in the palliative care team.

My first reaction was, “But we don't need palliation”. I feared what this meant. But the nurses

took the time to explain that it was much more than just nursing a dying person. It was about holistic support and understanding, ensuring that Brian could still ‘live’ as best he could in the time he had left.

When I asked my GP why doctors are so reluctant to suggest palliative care, he said some patients found it too difficult to deal with. Our feeling was that to know the truth about the diagnosis and what may lie ahead was essential.

Brian was able to enjoy the other services palliative care offered, whilst he was still well enough to appreciate it. He was able to join us at our daughter's debutante

ball. A nurse helped bathe and dress Brian and escorted him to the reception centre. She returned later to collect him and stayed with him until I returned home. It will be a memory that will be forever with us. And the photos we have of that night, we treasure enormously.

Brian also enjoyed the massage therapy offered until his death. As a family, we appreciated the work of the social worker. She helped Brian and I talk about difficult and confronting issues. She helped the children understand what was happening. The respite care offered was also a welcome relief. I needed the respite to remain strong for Brian and our children.

Although palliative care is much more than nursing, I cannot discount the wonderful support these nurses offered us. These ‘angels’ visited, medicated and reassured. They gave me

answers to questions that the doctors found too confronting to answer. The nurses gave Brian love and dignity to the end.

Now to his death. I have to be honest – I was fearful. We were all fearful of him dying at home. So a fortnight before Brian died, palliative care organised a bed in a local private hospital. But after a while, we worked out that home was indeed the best place for Brian. So we took him home, for the last time.

Palliative care gave us so much. The team gave Brian the nursing and the care he needed. They gave the rest of us the strength to see it through. They became a part of our family – they were like angels who would appear, see things right and then leave us to be a family again. My family would not have coped nearly as well without them. Palliative care is something not to be feared but embraced, if the need arises.”



Information for carers

Many people are fortunate to have a personal carer to help look after them. Usually a carer is a spouse or an adult child, but often other relatives, friends or neighbours will take on a significant caring role. Carers do not have to live with the person whom they support, but they provide care on a regular basis. Carers are a crucial – but often overlooked – part of the health system.

Caring can be a rewarding experience, but it can also be very draining and isolating, especially if you are caring for someone full-time. It is vital that as a carer you remember to take care of yourself too.

Organising palliative care services for the person you are supporting is an important step in helping both of you. By accepting assistance, you will be able to share your workload, which will help you to cope better with the demands of caring.

If you are a primary carer, it is also important to participate in discussions with the palliative care team and the person you are caring for, as any decisions made will affect you too. If the person you are caring for wants these discussions to remain confidential, you can explain that it will be easier for you both if you are involved in communication relating to their health care.

Respite care

Respite care is available to give you a break from your caring role. It can be given in your home, or the person you are looking after may be admitted to a respite care centre or, in some cases, a hospital or hospice.

Respite care can be for a couple of hours, overnight or for blocks of days. You can access respite care for any reason. For example, you may need time out to access health care for yourself; you may want to visit friends or other family members; or you just might want to catch up on some much needed sleep at home.

Some carers don't access the service because they feel guilty or concerned about leaving the person they are caring for. However, respite care is there because caring can be a very difficult role and can challenge your own sense of wellbeing. By allowing yourself a break, you will probably find that you can continue your caring role more effectively when respite care has finished.

The Department of Health and Ageing's Commonwealth Carer Respite Centre can provide emergency respite, as well as referring you to organisations that provide pre-planned respite services. It's best to make contact early on so they are aware of your situation, even if you don't have any immediate plans to access care.

You are eligible to access up to 63 days of residential respite care every calendar year. If you're receiving a Carer Allowance or Carer Payment from the Department of Human Services (Centrelink), you will continue to be paid when the person you are looking after is in residential care. Phone 1800 052 222 to discuss your situation.

“ It was very hard work, but I found that caring for my mother at home was one of the best things I could have done for her in her greatest time of need. ” Janice

Counselling and mentoring

Carers often experience a range of conflicting emotions. Talking confidentially with a counsellor or social worker about your feelings may help you cope better, learn communication strategies, and come to terms with changes in your life. You and your family may also be eligible for grief and bereavement counselling provided through the palliative care team.

Cancer Council telephone support group – Cancer Council offers a national telephone support group for carers. It runs twice monthly. For more information, call the Helpline on 13 11 20.

National Carer Counselling Program – This Carers Australia program provides short-term counselling. Carers Australia also runs support groups and has an online discussion forum for carers aged under 25. Visit www.carersaustralia.com or call 1800 242 636.

Young Carers Respite and Information Services Program – Administered through the Commonwealth Carer Respite and Carelink Centres, this program offers respite, practical help and social activities to carers under 25. Call 1800 052 222.

LifeCircle – Supports carers of people who wish to die at home. For enquiries, call 1300 364 673 or visit www.lifecircle.org.au.



Palliative care for young people

The majority of children and teenagers with cancer do not need palliative care. If a young person requires palliative care, it is specialised to focus on enhancing quality of life by addressing their unique physical, social, spiritual and emotional needs.

Elements of palliative care are often integrated early on with curative treatment, but sometimes symptom relief ends up becoming the key focus of care if the cancer cannot be controlled any longer.

The following organisations specifically support young people with cancer and their families by providing palliative care, financial assistance, counselling, resources and respite care. The hospital social worker will also be able to provide support, and may know of other useful networks in your local community.

CanTeen – An organisation for young people aged 12–24 living with cancer. It provides resources for adolescents, including information on palliative care and end-of-life issues and an interactive online forum. It also runs activities such as camps and social outings. Visit www.canteen.org.au or call 1800 226 833.

Redkite – A charity that supports young people and their families through cancer by providing emotional guidance, including bereavement support, financial assistance and educational services. For more information about its services, talk to the social worker at the hospital, visit www.redkite.org.au or call 1800 733 548.

Kids with Cancer Foundation Australia – Provides financial assistance to families of children with cancer and helps fund projects in public hospitals and oncology units. Call 1800 255 522 or visit www.kidswithcancer.org.au for more information or to discuss your family’s needs.

Palliative Care Australia – Has a detailed resource, *Journeys*, which helps families and carers prepare for the situations they may face as they live with their child’s illness. To access the resource, visit www.palliativecare.org.au and click on ‘Journeys’.



Palliative care provides support to families through practical, social, spiritual and emotional care. This often continues after a young person’s death.



Seeking support

When you are referred to palliative care or while you are having palliative care, you may have a range of mixed emotions. Many people feel shocked, fearful, sad or angry. Others may feel relief or have a sense of inner peace. On some days they may feel hopeful, and on other days, they may feel anxious. Some people may also have ongoing depression. If this happens to you, it is important to tell your doctor, as counselling or medication can help.

You may find that while some people you know are supportive, others may not even know what to say to you. This can be difficult, and you may feel lonely or upset. If you need to leave work due to the cancer, this may cause further sadness or stress.

It will probably help to talk about the different feelings you have. Your partner, family members and close friends can be a good source of support, or you might prefer to talk to:

- members of your treatment team
- a counsellor, social worker or psychologist
- your religious leader or spiritual adviser
- a support group – see next page
- Cancer Council Helpline 13 11 20.

If you have children, the idea of telling them about the cancer can be unsettling. Cancer Council's *Talking to Kids About Cancer* book may be helpful to you. There are also other free resources that may help you deal with the emotions that cancer can bring up.

If your family or friends have questions that you cannot answer, suggest they call the Helpline for more information.

Talk to someone who's been there

Coming into contact with other people who have had similar experiences to you can be beneficial. You may feel supported and relieved to know that others understand what you are going through and that you are not alone. There are many ways for you and your family members to connect with others for mutual support and to share information.

In these support settings, people often feel they can speak openly and share tips with others. You may find that you are comfortable talking about your diagnosis and treatment, your relationships with friends and family, and your hopes and fears for the future.

Ask your nurse, social worker or Cancer Council Helpline about suitable support groups and peer support programs in your area.

Types of support services*

Face-to-face support groups – often held in community centres or hospitals

Online discussion forums – where people can connect with each other at any time – see www.cancerconnections.com.au

Telephone support groups – for certain situations or types of cancer, which trained health professionals facilitate

Peer support programs – match you with a trained volunteer who has had a similar cancer experience, e.g. Cancer Connect.

** Not available in all areas*

Useful organisations and resources

Commonwealth Carer Respite and Carelink Centres –

This is a one-stop shop for accessing free, confidential, comprehensive information about services that can help with your care and assist you to live independently for as long as possible. Advisers can talk to you about equipment hire, nursing care, allied health services and programs such as Home and Community Care (HACC), which provides eligible people with short-term subsidised domestic help. Call 1800 052 222 or go to www.commcarelink.health.gov.au.

Palliative Care Australia and its state/territory member organisations – Peak organisations that promote palliative care information and standards. They have many useful resources, such as fact sheets, a specialist palliative care services directory, and detailed information on living with a life-limiting illness. Visit www.palliativecare.org.au.

Cancer Council services – Cancer Connections is an online discussion forum for people affected by cancer – see the website at www.cancerconnections.com.au. You may also be able to join a telephone support group for people with advanced cancer or their carers. This is a free and confidential program.

🗨️ Find out about practical and financial services and apply for them early on. Then be realistic that you will have to pay for some things yourself, and be grateful if you are granted some assistance down the track. 🗨️ *Xavier*



Pets Of Older Persons (POOPs) is a program for people receiving palliative care who don't have friends or relatives who can help look after their pets. In NSW, this program is run through the RSPCA. There is also an organisation in WA. Visit www.rspcansw.org.au or www.poopswa.org.au.

Financial support

For many people, an illness in the family can be a financial strain. This may be caused by extra out-of-pocket costs or from loss of income. For example, if you have to stay at home round-the-clock, household bills will increase and you and your family may eat more pre-packaged meals to save time and energy. You may need to pay for child care, transport, medication and equipment.

These extra costs can cause you and your family a lot of stress. Ask your social worker about any financial or practical assistance available to you and your carer, and apply for it as soon as possible. You may be eligible for assistance from the government, volunteer bodies, church groups or your local council.

Government assistance

The Department of Human Services (also known as Centrelink) offers financial support for people with a long-term illness and for primary carers. For Disability, Sickness and Carer enquiries, ring the Department on 13 27 17, or visit its website at www.humanservices.gov.au. Some of the different benefits available are described on the following page.

- The Sickness Allowance is for people who are temporarily unable to work due to illness. The Disability Support Pension is for people who are unable to work for two years or more because of their condition. Both are income and assets tested.
- The Carer Payment is for carers who provide constant care in the home of the person they are caring for. This payment is income and assets tested.
- The Carer Allowance is for carers who provide a significant amount of assistance, either in their own home or in the home of the person with cancer. The allowance is not means tested – you may be eligible for it if you are working or receiving another type of pension.

Cancer Council assistance programs

Your local Cancer Council may run programs to help people with cancer who need assistance with financial or legal matters.

For example, Cancer Council may be able to organise free or subsidised legal advice on issues such as advance care

directives, enduring powers of guardianship, will preparation and early access to your superannuation fund.

Talk to your social worker or contact Cancer Council Helpline **13 11 20** to talk about what is available in your state or territory.



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 Australia	www.canceraustralia.gov.au
Palliative Care Australia.....	www.palliativecare.org.au
Carers Australia	www.carersaustralia.com.au
Living, Caring, Working	www.livingcaringworking.com
CareSearch online resource	www.caresearch.com.au
Department of Health and Ageing.....	www.health.gov.au
Department of Human Services*	www.humanservices.gov.au
Commonwealth Carer Respite and Carelink Centres	www.commcarelink.health.gov.au
Bereavement Care Centre	www.bereavementcare.com.au

**Contact for information on Centrelink and Medicare benefits*

International

American Cancer Society.....	www.cancer.org
Macmillan Cancer Support.....	www.macmillan.org.uk
National Cancer Institute.....	www.cancer.gov



Question checklist

This question checklist may be a good starting point for you, as you think about the questions you want to ask your doctor. If your doctor gives you answers that you don't understand, it is okay to ask for clarification.

- Are there other treatments available that might cure the cancer?
- Will I receive medical treatment if I have palliative care?
- Which health professionals will be a part of my palliative care team, and who will coordinate my care?
- Do I have to pay for any palliative care services?
- Where will I receive palliative care?
- If I'm at home, what kind of help will be available?
- Can my family or carer access respite care or other assistance?
- Can I call the palliative care team at any time?
- How long will I need palliative care for? What is my prognosis?
- What will happen in the future to my body?
- I am worried about being unable to support my children financially and emotionally. What help is available?
- Can you help me talk to my family about what is happening?
- Are there any complementary therapies that might help?
- Can I get a second opinion about my need for palliative care?

For a detailed list of questions, go to www.palliativecare.org.au, and search for Palliative Care Australia's *Asking Questions Can Help: An aid for people seeing the palliative care team* resource.





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 plan

A document that outlines a person's specific wishes for future medical care.

advanced cancer

Cancer that has spread from where it started (the primary site) to other parts of the body. If it has spread to distant parts of the body, it is called metastatic advanced cancer.

alternative therapies

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

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.

complementary therapies

Supportive treatments that are used in conjunction with conventional or palliative treatment. They improve general health, wellbeing and quality of life, and help people cope with the side effects of cancer.

dietitian

A health professional who supports and educates patients about nutrition and diet during treatment and recovery.

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 Australia.

holistic care

Care that incorporates different

types of therapies and services to ensure that your physical, emotional, spiritual and practical needs are met.

hospice

A place that provides comprehensive care for people with a life-limiting illness. This may include inpatient medical care, respite care and end-of-life care for people who are unable to die at home.

life-limiting illness

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

malignant

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

metastasis

A cancer that has spread from a primary cancer in another

part of the body. Also known as secondary cancer.

morphine

A strong and effective pain-killer that is commonly used to treat people with cancer who have pain.

multidisciplinary (MDT) care

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

palliative care

The holistic care of people who have 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 nurse

A nurse who has specialised in

the field of palliative care and is very experienced in helping patients, families and carers with end-of-life care.

palliative care specialist (physician)

A doctor who has specialised in the field of palliative medicine, prescribing medical treatment for pain and other symptoms, as well as supporting and advising the other members of the palliative care team, the patient, family and carers.

palliative treatment

Medical treatment for people with advanced cancer to help them manage pain and other physical and emotional symptoms of cancer. Treatment may include radiotherapy, chemotherapy or other medication. It is an important part of palliative care.

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.

primary health care

A person's main health care, which is provided by a general practitioner (GP) or a community nurse. It can include initial tests and diagnoses of disease, health promotion, disease prevention, and chronic illness management.

primary health care provider

A health professional, such as a general practitioner (GP) or community nurse, who provides the first point of contact for a person to help them with a range of health care matters.

prognosis

The likely outcome of a person's disease.

quality of life

A person's comfort and satisfaction, based on how well their physical, emotional, spiritual, sexual, social and financial needs are met within the limitations of their illness.

radiotherapy

The use of radiation, usually

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

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.

secondary cancer

See metastasis.

specialist palliative care team

A multidisciplinary team with many health professionals who offer a range of services to improve a patient's quality of life and help with any problems they have. A community nurse or palliative care nurse usually coordinates the team.

terminal illness

An illness that is unlikely to

be cured and will result in somebody's death some time in the future. It may also be called a life-limiting illness.

References

¹ Temel, J et al. 2010. 'Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer', *The New England Journal of Medicine*. Vol. 363, pp. 733–42.

² Rowland, K & Schumann, S. 2010. 'Palliative Care: Earlier is Better', *The Journal of Family Practice*. Vol. 59, no. 12, pp 695–698.

³ NSW Ministry of Health. 2012. *The NSW Government Plan to Increase Access to Palliative Care 2012–2016*. Sydney: NSW Ministry of Health.



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.

Regional offices

Northern

Tamworth
02 6763 0900

Alstonville
02 6627 0300

Coffs Harbour
02 6659 8400

Western

Orange
02 6392 0800

Wagga Wagga
02 6937 2600

Southern

North Wollongong
02 4223 0200

Hunter and Central Coast

Charlestown
02 4923 0700

Erina
02 4336 4500

North Sydney

Crows Nest
02 9334 1600

Central and Southern Sydney

Woolloomooloo
02 9334 1900

Western Sydney

Parramatta
02 9354 2000

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**Palliative
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