



Australian Government

Cancer Australia

National Centre for

Gynaecological Cancers

NATIONAL CENTRE FOR GYNAECOLOGICAL CANCERS

Palliative care

What is palliative care?

Palliative treatment relieves cancer symptoms such as pain. It is available for all people who have cancer side effects, whatever their stage of cancer treatment. The way palliative care is managed differs in different regions of Australia due to changing resources and demands. It may be provided in or out of your home.

Palliative care does not try to cure disease but aims to help you and your family improve your quality of life by addressing physical, practical, emotional and spiritual needs associated with your illness.

Palliative care is particularly important for women with advanced cancer, who cannot be cured but want to live as comfortably as possible and without undue pain.

There are many places you can receive palliative care, depending on your situation, the area you live in, and the support offered by your family or carers. Palliative care can be provided in the home or in an aged care or residential care facility, palliative care units, hospitals, hostels or specialised hospices. Patients can move between these locations depending on the changing level of care and support required.

Accessing palliative care as early as possible can make things easier for you, your carers and family. For people with advanced cancer, it is best to make contact with a palliative care team early on so you can find out what different members of the team do and whether the services are relevant for you at the time. Even if palliative care services

are not required initially, you can become familiar with what is available if your needs change down the track.

You generally need a referral to access the specialist palliative care team, so ask your GP or nurse about this if you haven't had a discussion about how palliative care can help you. Once you've been referred, the team will always consult your GP about your care and treatment.

Myths about palliative care

There are many myths about palliative care. Because of this confusion, some people do not access palliative care until very late in their illness and they miss out on a lot of beneficial treatment and support. Below are some common myths about palliative care.

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Myth 1: Palliative care is for people who are about to die.

Fact: Palliative care is for people whose illness has not responded to the treatment available and is unlikely to be cured. It helps improve someone's quality of life so that they can live in comfort for as long as possible. This may be for weeks, months or years.

Myth 2: Palliative care is another term for euthanasia.

Fact: Palliative care and euthanasia are not the same thing. Palliative care is about coordinating medical and psychosocial services to optimise the comfort – and if possible, the capabilities – of a person with a life-limiting illness, without trying to prolong or shorten life. Euthanasia is the assisted death of someone who would prefer to die. It is illegal in every state and territory in Australia.

Myth 3: Palliative care draws out people's lives, making them a burden.

Fact: The role of the palliative care team is to provide specialised holistic care for the person. Palliative care is not about prolonging life; it is about improving quality of life and helping people at the end of their life in their preferred place of care.

Myth 4: A palliative care team will take away my independence and choices.

Fact: Palliative care gives you choices for enhancing your quality of life, which includes helping you maintain your independence for as long as possible. The palliative care team will offer you a number of options, but will respect your wishes if you don't want to take them up.

Will I still have medical treatment?

Yes, this is an important part of palliative care. Medical treatment for palliative patients is aimed at comprehensively managing the symptoms of cancer without trying to cure the disease. Often treatment is concerned with relief of pain or other symptoms caused by the cancer, but it can also include medication for physical side effects of treatments or emotional issues.

Some examples of palliative medical treatment are:

- radiotherapy to reduce pain when cancer has spread to the bones
- chemotherapy to stop the cancer growing into other organs
- palliative surgery to relieve pain or other problems
- medication to relieve constipation, nausea or pain
- medication for depression, anxiety or insomnia.

You can have palliative care for as long as you need.

Depending on your situation, you may live comfortably for months or years; on the other hand, your illness may advance more rapidly, which means the palliative care team will focus on your end-of-life needs. Whatever stage you're at, your team will continually assess your requirements and adjust your care as required.

It's important to give feedback to your doctor and your treatment team. They need to fully know your desires during treatment and at the end of your life. Let them know about any discomfort you have, and let them know what you expect in the way of pain relief.

The palliative care team

Your team will be made up of medical, nursing, allied health and volunteer 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. Assistance does vary in different regions, but the most common members of a palliative care team are

- nurse
- palliative care specialist or physician
- GP (family doctor)
- social worker
- counsellor or psychologist
- pastoral carer or spiritual adviser
- occupational therapist and physiotherapist
- dietitian
- volunteers.

You won't have to see all these people if they are not relevant for your needs – you can work out with your GP or nurse what services will benefit you the most.

Ask your palliative care team if they have a 24-hour telephone service and keep the number by the phone for any unexpected problems.

What happens if my carer can't look after me?

Respite care is to give carers a break from their caring role. Respite can be given in your home, or the person being looked after may be admitted to a respite care centre or, in some cases, a hospital.

It's best to make contact with the Commonwealth Carer Respite Centre early on, even if you don't have any immediate plans to access respite care. This allows your details to be recorded so that when your carer does need respite, either planned or in a crisis, your adviser will be aware of your situation. Contact the Commonwealth Respite and Carelink Centres on **1800 052 222*** during business hours or, for emergency respite support outside standard business hours, call **1800 059 059*** (*free call from local phones, mobile calls at mobile rates).

Do I have to pay?

Sometimes. The Commonwealth and State Governments fund core palliative care services so they are free in the public health system for you and your family, whether you receive care at home or in a public setting. However, there are some instances when you may need to contribute to the cost of care:

- If you need to use specialised equipment at home, there may be a hiring charge.
- If you require round-the-clock assistance and prefer to stay at home to receive it, you may need to organise and pay for your own nursing staff.
- Massage therapies used in conjunction with physiotherapy may attract a fee.

- If you have health insurance and are admitted to a private hospital, you may be required to pay an excess. Check with your health fund to see what you are covered for.
- Some respite services may charge a small fee.

Questions to ask your doctor

You may find this checklist helpful when thinking about the questions you want to ask your doctor about your illness and care. If your doctor gives you answers that you don't understand, it is okay to ask for clarification. You might also like to write down your own questions before seeing the doctor.

1. Are there any other treatments available that might cure the cancer?
2. Will I receive any kind of medical treatment if I have palliative care?
3. What health professionals will be a part of my palliative care team?
4. Who will coordinate my palliative care?
5. How much do the palliative care services cost?
6. Where will I receive palliative care?
7. If I am at home, how much help will be available for me (and my family or carer)?
8. Can my family or carer access respite care or other assistance?
9. How can I access the palliative care team? Can I contact them at any time?
10. How long will I need palliative care for? Do you know what my prognosis is?
11. What can I expect in the future? How will I feel? What will happen to my body?
12. I am worried about my children and supporting them financially and emotionally. What help is available for them?
13. Can you help me communicate with my family about what is happening to me?
14. Are there any complementary therapies that might help me?
15. Can I get a second opinion about my need for palliative care?

Further support or information

The Cancer Council Helpline (13 11 20) is a confidential service where you can talk about your concerns and needs with specialist cancer nurses. You can also ask for a free copy of the *Understanding Palliative Care* booklet.

Palliative Care Australia is the national organisation for palliative care. There is more information on their website (www.palliativecare.org.au), or telephone the national office in the ACT on 02 6232 4433.

Sources

We thank the following organisations for allowing their information to be used for this factsheet:

Cancer Council New South Wales
www.cancercouncil.com.au

National Cancer Institute (USA)
www.cancer.gov

NATIONAL CENTRE FOR GYNAECOLOGICAL CANCERS

CANCER AUSTRALIA

ABN 21075951918

The National Centre for Gynaecological Cancers is an Australian Government initiative to improve outcomes for women affected by gynaecological cancers, their families and carers, and to lessen the impact of cancer on their lives. It has been established by Cancer Australia.

Palliative care 2010

Last updated 2009. The information in this fact sheet was current at the time of publication. To check if it is the most up-to date version, please call 02 6217 9818

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