

Understanding Palliative Care



An information sheet for people with cancer, their families and friends.

Many people are not sure what palliative care and palliative treatment are. This information sheet gives a brief overview of the many ways these services can help people with advanced cancer. If you would like to know more, contacts for further information are given at the end of the sheet.

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

What is palliative care?

Palliative care aims to improve the quality of life of people with cancer and their families.

It helps you prevent and relieve symptoms of the cancer or your treatment, and helps you with the practical problems of daily life. Palliative care also involves spiritual and emotional care, and the support of family and other carers.

What is palliative treatment?

Palliative treatment is medical treatment that eases symptoms but is not expected to cure the disease. For example, radiotherapy or medication to stop cancer that has spread to the bones causing pain.

Common questions

Where do I receive palliative care?

You may be cared for in your own home (through community palliative care or community nursing) or at any general hospital or palliative care hospital.

How can I receive palliative care?

Your hospital doctor or nurse, or your GP can put you in touch with a palliative care team. You can also refer yourself, in some cases. A community palliative care team will always consult with your GP about your treatment.

If your carer is unwell or needs a break, you can be cared for in a public or private hospital, if you have private health insurance. This is called respite admission. Ask your GP to arrange this.

Do I have to pay?

No – palliative care services are free. You may have to pay for admission to a private hospital.

When would I use it?

It is best to make contact with a palliative care team early in your illness. You can learn about what the team do and build a relationship so they won’t be strangers if you decide to use them. It is good to treat symptoms before they become too troublesome. It is often easier to treat a symptom (e.g. pain) early rather than once it takes hold.

“I was really surprised to find out that the service was free.”

Help

Hope

The palliative care team

The palliative care team is there to help make life easier for you in any way it can. If you are at home, the community palliative care team can help to keep you out of hospital by checking on your health either by phone or by visiting you. The team may include:

Nurse

- co-ordinates the service, works out what help you need and makes sure you have enough pain relief
- talks to you about how to take your medication, manage your pain, bowels and insomnia, and practical things like how to pace your day
- organises the other people in the team to see you and any other external services such as home nursing you may need.

Palliative care specialist (doctor)

- treats any pain, nausea, constipation, anxiety or depression, and other symptoms you may have
- can visit you in your home, as well as in hospital, nursing home or hostel
- communicates closely with the oncologist and GP so your treatment is well co-ordinated.

Social worker, counsellor and psychologist

- give emotional support and may help you to work out who among your friends, family and neighbours you can ask to be your support team
- discuss ways of coping and emotionally supporting your children
- tell you about useful services such as home respite care, meal services, disabled parking authority stickers, personal alarms, aged care services and local community aid, respite services
- make sure you know about any financial support you can get

The palliative care team may have a 24-hour telephone service.

- teach you meditation and relaxation exercises to help ease pain and emotional concerns.



Pastoral carer

- can talk over spiritual issues with you
- can discuss emotional issues, as many are trained counsellors.

Occupational therapist and physiotherapist

- help you with the physical side of your daily activities, such as walking, and getting into and out of bed and chairs safely
- talk to your carers about the best ways to help you sit and stand
- give you exercises to get a part of the body moving again after it has not been used for a while
- may give you aids such as a walking frame or a device to help you put on your socks (sometimes it is the simplest things that can make a big difference!)
- may also work with a massage therapist for relief of stiff and sore muscles or swelling.

Dietitian

- works out the best eating plan for you.

These health professionals are only used if and when necessary; you do not have to see everyone listed here. The palliative care team can also refer you to other services, if needed.

Myths about palliative care

Many people think that palliative care is only for people who are about to die, but palliative care can be given at any stage of advanced disease. You may also have palliative care for respite care or symptom control such as pain.

Some people also worry about seeing the palliative care team because they mistakenly think they carry out euthanasia. The palliative care team will not speed up or delay death. Discussing these concerns with a member of

your local palliative care service will help put your mind at ease.

“I was in shock when my doctor told me I was having palliative care – I thought I was going to die in a matter of weeks. It took me a while to understand that for me it just meant keeping the disease under control.”

An example of palliative care in practice

The following example shows the range of services available. Unfortunately the availability of these services varies from area to area. Call the Cancer Council Helpline on 13 11 20 or ask your GP about what services are available in your local area.

Margaret has advanced breast cancer. The cancer has spread to her bones and she has a broken leg. She has had some radiotherapy and has just moved back home when her GP calls in the palliative care team to help.

First the nurse visits Margaret at home to see how she is managing and what sort of help she is going to need. Margaret is very emotional, still has some pain and is worried about how she will cope at home.

Margaret tells the nurse about her fears, which include how her young children are coping and money problems. She also has trouble getting around the house, standing up and picking things up off the floor.

The nurse calls in the palliative care specialist, who changes Margaret's medication so her pain is better controlled, and prescribes a laxative for the constipation.

Next to visit is the social worker, who offers Margaret emotional support. She gives her advice on how to help young children who have a parent with cancer cope. The social worker talks to Margaret's husband about how he is managing and tells him about the

carer's allowance, which will give them some extra money.

The occupational therapist also visits Margaret and works out what sort of aids could help her. She is given a walking frame, a toilet raiser so it is easier to get up off the seat, a rail to help with getting out of bed and a tool to pick things up off the floor. The occupational therapist shows Margaret's husband the best way to help her in and out of chairs and bed.

The palliative care specialist arranges for a community nurse to visit Margaret twice a week to help with showering and bowel care. The community nurse will keep an eye on how Margaret is going, and will call the palliative care specialist if any problems come up. The palliative care specialist will also keep in touch with Margaret by phone to check how she is going.

“It's great just knowing there is somebody at the end of the phone that I can talk to.”

Seeking support and information

For more information call the Cancer Council Helpline on 13 11 20.

Palliative Care Association of New South Wales
Level 11, 418A Elizabeth Street
Telephone: (02) 9282 6436
Email: linda@palliativecarenewsw.org.au
Website: www.palliativecarenewsw.org.au

The Cancer Council Helpline

The Cancer Council Helpline is a service of The Cancer Council NSW. It is a telephone information and support service for people affected by cancer. It is a confidential service where you can talk about your concerns and needs with specialist cancer nurses. The

nurses can send you written information and put you in touch with appropriate services in your own area.

You can call the Cancer Council Helpline on 13 11 20, Monday to Friday, 9am to 5pm, for the cost of a local call. The tele-typewriter (TTY) number for deaf or hearing-impaired people is (02) 9334 1865.

As well as English, the Helpline is offered in the following languages:

Cantonese and Mandarin	1300 300 935
Greek	1300 301 449
Italian	1300 301 431
Arabic	1300 301 625

To access the Cancer Council Helpline in languages not on this list, call the Translating and Interpreting Service on 13 14 50.

Understanding Palliative Care

An information sheet for people with cancer, their families and friends.

First published September 2003. Revised November 2004, January 2006.

© The Cancer Council New South Wales 2006

ISBN 1 92104 116 1

Acknowledgements

We thank the reviewers of this information sheet: Dr David MacKintosh, Staff Specialist in Palliative Care, Greenwich Hospital; Eva Cranston, Clinical Nurse Consultant in Palliative Care, Greenwich Hospital; Dr Melanie Lovell, Palliative Care Fellow, Sacred Heart Hospice; Peta McVey, Clinical Nurse Consultant, Neringah Hospital, Hope Healthcare; Dr Cynthia Parr, Staff Specialist in Palliative Care, Neringah Hospital, Hope Healthcare; Dr Robert Jaffrey, Senior Staff Specialist in Palliative Care, Neringah Hospital, Hope Healthcare; Anne Casey, Cancer Council Helpline Consultant; and Beverly Noble, Cancer Voices NSW.

Editor: Jenny Mothoneos

Writer: Helen Francombe

Cartoonist: Greg Smith

The Cancer Council New South Wales

The Cancer Council is the leading cancer charity in New South Wales. 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 patients, and raising funds for cancer programs.

This information sheet is funded through the generosity of the people of New South Wales. To make a donation to help defeat cancer, visit The Cancer Council's website at www.cancercouncil.com.au or phone 1300 780 113.

Before commencing any health treatment, always consult your doctor. This information sheet is intended as a general introduction to the topic and should not be seen as a substitute for your own doctor's or health professional's advice. All care is taken to ensure that the information contained here is accurate at the time of publication.

The Cancer Council New South Wales
153 Dowling Street
Woolloomooloo NSW 2011
Cancer Helpline: 13 11 20
Telephone: (02) 9334 1900
Facsimile: (02) 9334 1741
Email: feedback@nswcc.org.au
Website: www.cancercouncil.com.au



Building a
Cancer Smart
Community