



## 8. PALLIATIVE CARE

People with advanced cancer may need to use palliative care services for any number of reasons at any stage after curative treatment stops. The term palliative care covers a lot of ground and you may have many questions about what it means for you.

## What is it?

Palliative care is the support of people with serious illnesses considered to be chronic if not incurable. It is a holistic approach that aims to achieve the best possible quality of life for you and for those close to you.

Palliative care is not just for people who are “waiting to die” and is not limited to physical health or pain control. Rather, it encompasses the full range of needs you or those around you may have including psychological or social support or a broad range of services.

## Where is it provided?

Where you receive palliative care will depend on your circumstances. At any given time, it may be provided in your home, a hospice, a hospital or a nursing home.

Palliative care teams are particularly useful in assisting people who are being cared for at home. If it is difficult, or not advisable for you to remain at home you may need to be admitted to a hospital with palliative care beds or to a specialist palliative care unit or hospice.

## Who provides it?

Palliative care may be provided by your specialist, doctor, community nurse and other members of your health care team. However, if you develop problems that are complex or difficult to manage, then your doctor may refer you to health care workers who have training and experience in palliative care services, or to a specialist palliative care team.

Given your experience with cancer, the list of health workers providing palliative care may well be familiar. In this case, all of them will have been trained to meet your needs at this stage of your illness, and be more focused on your quality of life than on a cure.



• Seek palliative care as soon as you think you may need it, because that is when it is most effective. People often say they wish they had known about the services earlier.

## Professional health workers

### Doctors

Your doctor or treating specialist (if you are using one) is likely to be co-ordinating your care in the first instance. This doctor will oversee your care at home, liaise with the community nurse and refer you to other support people if needed.

If and when your care becomes difficult for your own doctor to manage they may refer you to specialist palliative care doctor or team and if necessary, arrange your admission to a hospital, palliative care unit or hospice.

Palliative care specialists are doctors who can prescribe treatment for your symptoms, liaise with your oncologist and doctor and refer you to other services. These doctors may or may not be part of a specialist palliative care team or service.

### Nurses

Palliative care nurses may either work for the community nursing service or in a specialist palliative care team. They may monitor your symptoms and help you with your medications, dressings, personal hygiene and day-to-day care.

To access community nurses who do palliative care, ask your doctor to refer you or contact them through your local community health centre.

### Social workers

Social workers can provide social and emotional support to you, your carers and your family. They can help you find services such as in-home respite care, meal deliveries, personal alarms, laundry services and financial assistance.

### Counsellors and psychologists

These mental health workers can help you with relationship or family issues, adjusting to and coping with new situations, show you ways of dealing with anxiety and depression, and provide grief counselling to your family and caregivers.

### Occupational therapists

Occupational therapists can suggest modifications to your home to aid your independence and ensure your safety. They can also provide special equipment and show you how to use it, as well as advise your caregivers on lifting, transport and hygiene.

## Physiotherapists

Palliative physiotherapy can help you manage pain, incontinence, lymphoedema (swelling caused by lymphatic problems) and other symptoms. A physiotherapist can also help you recover from operations and work on your mobility.

## Dieticians

Dietary advice may become more important as your illness progresses, especially if your appetite and digestive system are not co-operating with your will to remain as healthy as you can. A dietician can help with eating plans and nutritional supplements, among other things.

## Volunteers

Also available are the many people who donate time and can take you to your medical appointments or shopping, help you with housework and gardening and can provide respite for your caregivers.

## Specialist teams or services

Although many health care workers offer palliative care as part of a wider range of services, some health professionals specialise in such care. They are usually part of a specialist palliative care team or service, and can include doctors, nurses and any of the health professionals listed above.

Members of these teams are highly experienced in helping people with difficult and complex problems and are very good at talking with people about their condition.<sup>71</sup>

You can talk to your doctor or nurse if you would like access to a specialist palliative care service, or you can contact a service directly. Palliative Care

Australia has a National Palliative Care Service Directory (see contact details at the end of this chapter). Receiving care from a specialist palliative care service does not mean you need to stop seeing your other doctors. Palliative care can complement other forms of treatment at any time during your illness.



## When and why should I use it?

Some people avoid palliative care services because they think they are “not at that stage yet”. Referral to a palliative care service is not governed by the stage of your disease or how long you are expected to live. Such care is appropriate if and when you, your carer or family identify needs that are complex or simply not being met. Your needs may be medical, emotional, social or spiritual.

### The benefits of palliative care include:

- Practical help that may allow you to be cared for at home or in another place of your choice.
- Co-ordination of your care between the many different people involved.
- Information about all aspects of your care.
- Physical, emotional and social support for you, your caregivers and family.
- Help to make practical changes around the house to reduce stress and frustration.
- Help to identify your priorities and to live as well as possible for as long as possible.
- Information and support on bereavement, loss and grief.



### Q&A

Q: How long is it feasible for me to remain at home alone?

A: You can stay at home for as long as you wish, provided you have adequate support from community nurses and carers, and your symptoms are manageable. If you live alone, a community nurse will discuss with you how much help you need with daily living. Your carers need to be able to cope with any decline in your health and you need to be aware that the risk of distressing symptoms, such as a catastrophic bleed, may make hospitalisation necessary in some cases.

(Source: Helen Moore, Service Manager, Palliative Care, Calvary Health Care Sydney)

## How much will it cost?

The cost of palliative care depends on the services you use. Some core services are free in the public health system but you may have to contribute to the cost of care in other instances.

Private health insurance does not always cover your expenses. You may find yourself paying out of pocket for services such as specialised equipment, 24-hour nursing staff, private hospital stays, some respite care or complementary or alternative treatments.

Some service and programs may be able to help you with some of the out-of-pocket expenses. It may help to call the **Cancer Council Helpline** on **13 11 20** for information about this.

## Is it right for me?

Your doctor or your most trusted health professional, can help you decide if palliative care is right for you. You and your caregiver can prepare for this decision by filling out the Needs Assessment Tool-Patients & Families included at the end of this booklet. This tool will document your needs and those of your family member(s) or caregiver(s) so you can discuss them with your doctor. They will also direct you to the sections in this booklet that can give you more information if you want to read more to help yourself.

If you or your caregiver has identified needs on the Needs Assessment Tool-Patients & Families that, for whatever reason, are not being met under your existing circumstances, palliative care may be a solution.



### Q&A

**Q:** What should I do when all treatment has stopped and my oncologist has told me there is nothing more to be done?

**A:** Palliative treatment can come into play when all curative treatment has stopped and can continue until the very end. Palliative chemotherapy and radiotherapy are commonly used to reduce symptoms, for instance. Your oncologist may still be involved but the palliative care specialist will probably be looking after your overall care.

(Source: Helen Moore, Service Manager, Palliative Care, Calvary Health Care Sydney)

## How do I get access to care?

Some palliative care services need to have a referral from your doctor, while others can accept a referral from you, a family member or friend, community health centres and local hospitals. Your doctor, or the individual services, will be able to tell you when formal referrals are needed.

### Talking with your Doctor

It is sometimes hard to tell your health professional that you need more help. Research has shown that it helps to take a list of questions to consultations with

your cancer doctors.<sup>82</sup> That way, you are both focused on what is important and relevant to you at that time.

The Needs Assessment Tool-Patients & Families (pg 116) can help you identify your concerns and may be a way of raising palliative care as an option for you.

### For more information

The following organisations can provide information on palliative care and what services are available in your area:

- **Commonwealth Carelink Centre** – phone **Freecall 1800 052 222**, go to **[www.commcarelink.health.gov.au](http://www.commcarelink.health.gov.au)** or visit your local Carelink Centre (phone the Freecall number for locations).
- **Palliative Care Australia** – phone **(02) 6232 4433** to use the National Palliative Care Service Directory to find details of services in your area or go to **[www.pallcare.org.au](http://www.pallcare.org.au)**

**Alternatively, you can contact the palliative care body in your state:**

- **Palliative Care Association of NSW** – phone **(02) 9334 1891**, or go to **[www.palliativecarensw.org.au](http://www.palliativecarensw.org.au)** for a directory of services listed by area.
- **Palliative Care Association of Victoria** – phone **(03) 9662 9644**, or go to **[www.pallcarevic.asn.au](http://www.pallcarevic.asn.au)** and select the “Resources and Links” option to search by postcode for services in your area.
- **Palliative Care Association of Queensland** – go to **[www.pallcareqld.com](http://www.pallcareqld.com)** and select the “Resource Centre” link, then search by services.
- **Palliative Care Council of SA** – go to **[www.pallcare.asn.au](http://www.pallcare.asn.au)** and select “Location of Services” for a list of hospice, palliative care, nursing and domiciliary services in each area.
- **Palliative Care WA** – go to **[www.palliativecarewa.asn.au](http://www.palliativecarewa.asn.au)** and select “Location of Services”.
- **NT Department of Health and Community Services** – go to **[www.nt.gov.au/health/index.shtml](http://www.nt.gov.au/health/index.shtml)** and select “A-Z Topics and Services”.
- **ACT Health** – go to **[www.health.act.gov.au/c/health](http://www.health.act.gov.au/c/health)** and select “Health Services”.

- **Tasmanian Department of Health and Human Services** – go to [www.dhhs.tas.gov.au](http://www.dhhs.tas.gov.au) and select “Service Directory”.

**Other information resources include:**



- The Cancer Council booklet Understanding Palliative Care is available by calling the **Cancer Council Helpline on 13 11 20**.
- Cancer Council Victoria’s booklet When Cancer Won’t Go Away, available by calling the **Cancer Council Helpline on 13 11 20**.



**FACTS**

There are many myths and misconceptions about palliative care:

**Myth:** Palliative care is only for people who are dying.

**Fact:** Palliative care is not about dying; it is about living as well as you can for as long as you can. It can be used at any stage during your illness after curative treatment has stopped.

**Myth:** Palliative care is the same as euthanasia.

**Fact:** Palliative care may not be focused on prolonging life, but it is certainly not there to shorten it<sup>72</sup>. Euthanasia is assisted suicide, whereas palliative care is assisted living.

**Myth:** Palliative care gives pain relief in increasing doses, which eventually causes respiratory depression and death.

**Fact:** Palliative care services help manage your pain, often using drugs such as morphine. Some people think the use of pain-killing drugs causes early death.<sup>73</sup> Research does not support this. Minor respiratory depression may occur when strong pain killers are introduced but this settles down quickly. Opioid pain killers should be carefully managed so as to relieve pain without causing excessive sleepiness. Palliative care doctors and nurses are trained and experienced in administering such medications to ensure maximum benefit with minimum harm.<sup>74</sup>

**Myth:** Palliative care achieves nothing.

**Fact:** Palliative care is an active approach to symptom management and emotional and social support. The sophisticated medical technology it uses can control symptoms and improve your quality of life.

**Myth:** People who are referred to palliative care give up and die.

**Fact:** People who use palliative care may live longer<sup>75</sup>. They also report a better quality of life and more satisfaction with their care.<sup>76,77</sup> There are also benefits for caregivers and families.<sup>78-81</sup>

**Personal Notes**

A series of horizontal dotted lines for taking notes, located on the right side of the page.