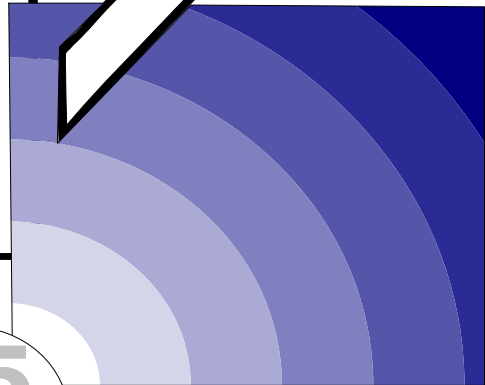
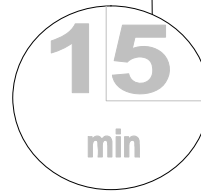


# CLIP

15 minute Worksheet



## Introduction to palliative care

### 1: What is palliative care?

**Introductory level**

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#### **Aim of this worksheet**

To review the basic principles of palliative care in adults and children.

#### **How to use this worksheet**

- You can work through this worksheet by yourself, or with a tutor.
- Read the case study below, then work on the questions overleaf.
- The work page is on the right side, the information page is on the left.
- Work any way you want: you can try answering from your own knowledge (in which case fold over the information page), you can use the information page (this is not cheating- you learn as you find the information), or you can use other sources of information
- It should take you about 15 minutes. If anything is unclear, discuss it with a colleague.
- If you think any information is wrong or out of date let us know
- Use the activity on the back page and take this learning into your workplace.

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## Defining palliative care in adults and children

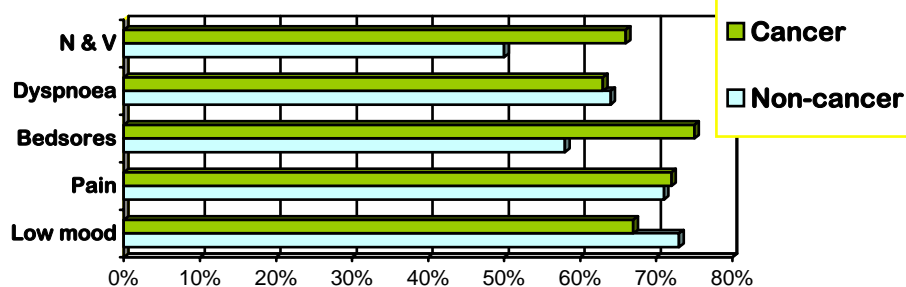
### Palliative care

- is the right of every adult and child and the duty of every professional.
- is about the holistic care of adults and children with life-limiting and life-threatening illness
- closely involves the partner, family or relatives
- includes care of the dying and bereavement support (although 50% of adults and nearly 100% of children in many hospices will return home after their first admission)
- can occur in any setting, but both adults and children spend most of their illness at home
- aims to support existing services, collaborating with them to tailor the care to the patient
- requires good symptom control (physical and psychological)
- is not limited to cancer (up to 18% of adults and most children in hospices do not have cancer)
- has no age limits (although adult and children's services usually work separately)
- does not prolong or hasten dying and is the realistic alternative to euthanasia and patient assisted suicide.

It has also been called "A safe place to suffer" *Averil Stedeford (Palliative Medicine, 1987; 1: 73-4):*

- Effective physical symptom control is essential
- Some psychological suffering will be left
- It is therapeutic for this suffering to be expressed
- Expression will only occur if it feels safe for the distressed person
- Removal of all the suffering is not always possible
- Expression can be enabled almost anywhere (ie. it is not dependent on a hospice building)

## Symptoms left unrelieved



Addington-Hall J et al. *Palliative Medicine*, 1998; 12: 417 - 427

Two thirds of adults not receiving palliative care remain very distressed by their symptoms.

This figure of unrelieved distress is similar for non-cancer adults.

There are no comparative figures for children with life-threatening or life-limiting illness.

There is still much work to be done in palliative care.

## Palliative care in children

1,100 children die each year from conditions for which there is no reasonable hope of cure: 40% from cancers, 20% from heart disease, and 40% from other life-limiting conditions. There are many similarities with adult palliative care (see above), but there are also important differences: 1) a wider range of conditions, 2) the longer time span of conditions (often years), 3) issues around their physical and intellectual development, 4) much less involvement with cancer, 5) the fact that conditions may affect several members of the same family, 6) the intensity of support needed for the whole family, 7) the presentation of symptoms, 8) the effects of drugs on young children and 9) legal issues of treating and caring for children.

## When should palliative care start?

**Adults:** in cancer patients palliative care may start at diagnosis, although it is more usual for it to start when cure is no longer possible. In neurological disease such as motor neurone disease patients, palliative care can start at diagnosis for patients since their prognosis can be much worse than many cancers. For other neurological diseases (eg. multiple sclerosis) they may be first seen by the rehabilitation services, and only referred at a late stage to palliative care. In AIDS patients treatment is aimed at controlling the disease and this has greatly limited the need for referral to palliative care services, but patients do continue to succumb to AIDS, and palliative care now sees more patients with AIDS-related dementia.

**Children:** four groups are recognised:

- Group 1: conditions for which cure is possible, but may fail (eg. cancer, irreversible failure of heart, liver or kidney)
  - Group 2: conditions where long-term treatment aims to prolong life, but death is still possible (eg. cystic fibrosis)
  - Group 3: progressive conditions lasting many years (eg. Batten's disease, mucopolysaccharidoses)
  - Group 4: conditions causing severe disability which increase susceptibility to health complications which may cause sudden deterioration (eg. disabilities following severe brain or spinal cord injury, including some with cerebral palsy).
- Groups 1 and 2 may need palliative care at times of uncertainty or in the terminal stages.  
Groups 3 and 4 may need support from palliative care services on a regular basis.

NB. As medical care improves, some of these children are now growing into their teens and early adulthood.

**Reflect**

The following have all been used to describe palliative care  
**Ring** those descriptions that you feel are the closest to reality

- |                                       |                   |                        |
|---------------------------------------|-------------------|------------------------|
| The right of every patient            | Terminal care     | Cancer care            |
| Physician assisted suicide            | Symptom control   | Euthanasia             |
| The duty of every professional        | Hospice care      | Home care              |
| Care of advanced, progressive disease | Care of the dying | A safe place to suffer |

**Reflect**

**In one study, what percentage of cancer adults do you think remained very distressed by the following symptoms?**

|                     |               |     |            |     |
|---------------------|---------------|-----|------------|-----|
| Pain                | less than 20% | 50% | Two thirds | 80% |
| Nausea and vomiting | less than 20% | 50% | Two thirds | 80% |
| Breathlessness      | less than 20% | 50% | Two thirds | 80% |

**Reflect**

**Do you think these figures would be different for non-cancer patients?**

- Lower      About the same      Higher

**Write**

**List the similarities and differences in the palliative care of adults and children**

**Similarities**

**How are children different?**

**Reflect**

**When should palliative care start?**

|  |              |                                 |                   |
|--|--------------|---------------------------------|-------------------|
| For a cancer adult:                    | at diagnosis | when cure is no longer possible | in the last weeks |
| For motor neurone disease              | at diagnosis | when cure is no longer possible | in the last weeks |
| For a child with severe cerebral palsy | at diagnosis | when cure is no longer possible | in the last weeks |

## FURTHER ACTIVITY: What is Palliative Care?

Over the next week observe

–how many patients have palliative care needs now

– how many patients may have palliative care needs in the future.

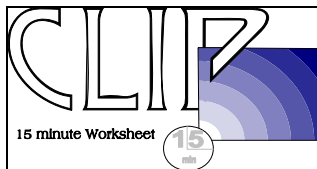
## FURTHER READING: What is Palliative Care?

### Journal articles

- Belasco JB. Danz P. Drill A. Schmid W. Burkey E. Supportive care: palliative care in children, adolescents, and young adults--model of care, interventions, and cost of care: a retrospective review. *Journal of Palliative Care*. 2000; **16**(4): 39-46.
- Davies E. Higginson IJ. Systematic review of specialist palliative day-care for adults with cancer. *Supportive Care in Cancer*. **13**(8): 607-27, 2005.
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- Gilmer MJ. Pediatric palliative care: a family-centered model for critical care. *Critical Care Nursing Clinics of North America*. 2002; **14**(2): 207-14.
- Goldman A. Recent advances in palliative care. Importance of palliative care for children is being increasingly recognised. *BMJ*, 2001; **322**:234.
- Horsburgh M. Trenholme A. Huckle T. Paediatric respite care: a literature review from New Zealand. *Palliative Medicine*. 2002; **16**(2): 99-105.
- Jones R. Acute hospital-based palliative care services for the older person. *British Journal of Nursing*. **14**(11): 596-600, 2005.
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- Makin W. Finlay IG. Amesbury B. Naysmith A. Tate T. What do palliative medicine consultants do?. *Palliative Medicine*, 2000; **14**(5):405-9.
- Oliver D. Webb S. The involvement of specialist palliative care in the care of people with motor neurone disease. *Palliative Medicine*, 2000; **14**(5):427-8.
- Praill D. Keeping up the pressure: pushing palliative and hospice care higher up the political agenda. *International Journal of Palliative Nursing*. **12**(2): 81-2. 2006.
- Roy DJ. The times and places of palliative care. *Journal of Palliative Care*. 2000; **16** Suppl:S3-4.
- Shuster JL Jr. Palliative care for advanced dementia. *Clinics in Geriatric Medicine*, 2000; **16**(2):373-86.
- Szlosarek PW. Recent advances in palliative care. United Kingdom continues to lead in palliative care. *BMJ*, 2001; **322**:234.
- Stedeford A. A safe place to suffer. *Palliative Medicine*, 1987; **1**: 73-4
- Thorns AR. Gibbs LM. Gibbs JS. Management of severe heart failure by specialist palliative care. *Heart*, 2001; **85**(1):93.
- Twycross RG. Palliative care in the past decade and today. *European Journal of Pain*, 1999; **3**(SUPPL. A): 23-29.
- Webster J. Kristjanson LJ. "But isn't it depressing?" The vitality of palliative care. *Journal of Palliative Care*. 2002; **18**(1):15-24.

### Resource books and websites

- Association for Children with Life-threatening or Terminal Conditions and their Families [www.act.org.uk](http://www.act.org.uk)
- Cicely Saunders : *selected writings 1958-2004*. Oxford : Oxford University Press, 2006.
- Directory of Hospice and Palliative Care Services in the United Kingdom and Republic of Ireland* . London : Hospice Information Service at St Christopher's, 2006. Also [www.hospiceinformation.info](http://www.hospiceinformation.info)
- Future for Palliative Care. Issues of Policy and Practice*. David Clark, ed. Oxford: Oxford University Press, 1993
- Introducing Palliative Care* 3rd ed. Twycross R Publisher Abingdon: Radcliffe Medical Press, 1999.
- Oxford textbook of Palliative Care for Children*. Ann Goldman, Richard Hain, Stephen Liben, eds. Oxford : Oxford University Press, 2006.
- Oxford Textbook of Palliative Medicine* 3rd ed. Doyle D, Hanks G, Cherny NI, Calman K eds. Oxford : Oxford University Press, 2003.
- Providing a Palliative Care Service : towards an evidence base*. Oxford : Oxford University Press, 1999.
- Textbook of Palliative Nursing*. Betty R. Ferrell, Nessa Coyle, eds. 2nd ed. Oxford : Oxford University Press, 2006.
- The philosophy of palliative care : critique and reconstruction*. Fiona Randall, Robin S. Downie. Oxford : Oxford University Press, 2006.



**Current Learning In Palliative care**  
An accessible learning programme for health care professionals

### 15 minute worksheets are available on:

- An introduction to palliative care
- Helping the patient with pain
- Helping the patient with symptoms other than pain
- Moving the ill patient
- Psychological needs
- Helping patients with reduced hydration and nutrition
- Procedures in palliative care
- Understanding and helping the person with learning disabilities
- The last hours and days
- Bereavement

Also available online on

[www.helpthehospices.org.uk](http://www.helpthehospices.org.uk) (click on 'e-learning')