

CLiP

15 minute Worksheet



Introduction to palliative care in adults

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.

How to use this worksheet

- You can work through this worksheet by yourself, or with a tutor.
- Read the case study below, and then turn to the Work page overleaf.
- Work any way you want. You can start with the exercises on the Work page using your own knowledge. The answers are on the Information page - this is not cheating since you learn as you find the information. Alternatively you may prefer to start by reading the Information page before moving to the exercises on the Work page.
- This CLiP worksheet should take about 15 minutes to complete, but will take longer if you are working with colleagues or in a group. If anything is unclear, discuss it with a colleague.
- If you think any information is wrong or out of date let us know.
- Take this learning into your workplace using the activity on the back page.

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Palliative care

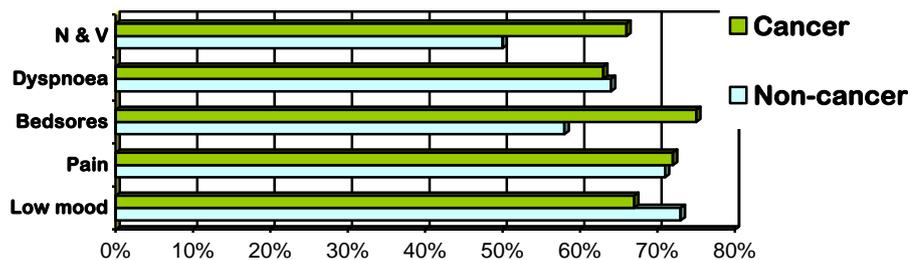
- Is the right of everyone and the duty of every professional involved in their care;
- Is about the holistic care of adults with life-limiting and life-threatening illness;
- Closely involves the partner, family and relatives;
- Includes care of the dying and bereavement support (although 50% of adults and nearly 100% of children in many hospices will return home after their first admission);
- Can occur in any setting, but most people spend most of their illness at home;
- Aims to support existing services, collaborating with them to tailor the care to the needs of the patient;
- Requires good symptom control (physical and psychological);
- Is not limited to cancer (up to 18% of adults in hospices do not have cancer);
- Has no age limits;
- Palliative care is a dialogue; eliciting ongoing concerns and fears from the person/patients and negotiating care plans with them along their journey;
- Does not prolong or hasten dying and is the realistic alternative to euthanasia and patient assisted suicide;

Palliative care is a dialogue – a two way process of communication starting with listening. Establishing this dialogue is the starting point for effective palliative care.

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 of suffering 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).

Cancer and non-cancer patients



This figure of unrelieved distress is similar for cancer and 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.

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

Palliative care has often centred around caring for patients at the end of life, most with cancer. In the last 20 years however, more effective treatment means many life-threatening conditions have become more chronic with survival times of years or even decades. Life-limiting conditions can be non-cancer, but better diagnosis and treatment is making cancer increasingly chronic. It is no longer true that different conditions have distinct disease trajectories and many conditions overlap in prognosis and have a wide variety of disease trajectories. Average survival times of cancer now overlap those of non-cancer:

- Early breast cancer - over 90% survive for 5 years.
- Dementia - of those aged 60-69 around half survive 5 years, with an survival time of 4-6 years
- Multiple sclerosis - over 98% survive 5 years with an average survival of nearly 50 years.
- Lung cancer - the overall 5 year survival is around 15%, but localized tumours can have a 50% 5 year survival.
- Motor neurone disease - the commonest form has a very low 5 year survival of 7%.

When should palliative care start?

In adult *cancer patients* palliative care can start at diagnosis, although it is more usual for it to start when cure is no longer possible. In patients with *neurological disease* such as motor neurone disease patients, palliative care is more likely to start at diagnosis since their prognosis can be worse than many cancers. For other neurological diseases (eg. multiple sclerosis) they may be first seen by the rehabilitation services, and only a minority will be referred at a late stage to palliative care. Patients with *advanced dementia* are usually cared for by specialised services, but palliative care input can be needed in the late stages. Patients with progressive *respiratory disease* and those with *end-stage heart failure* have variable patterns and they will need palliative care at any stage that they have severe or complex problems. Patients with *renal failure* often benefit from temporary palliative care input at any stage since they often have complex needs.

Choose

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

Think

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%

Think

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

Lower About the same Higher

Choose

Ring the average proportion of patients surviving 5 years with the following conditions

Proportion surviving 5yrs ('the 5 year survival')

Early breast cancer	<15%	half	>90%
Dementia	<15%	half	>90%
Multiple sclerosis	<15%	half	>90%
Lung cancer	<15%	half	>90%
Motor neurone disease	<15%	half	>90%

Think

When do you think palliative care should start?

For a cancer patient	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 someone with renal failure	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.

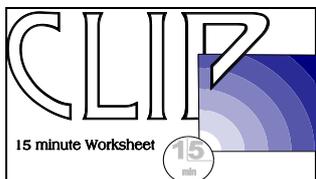
FURTHER READING: What is Palliative Care?

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.
- Doyle D. (2003) Editorial. *Palliative Medicine*. **17**(1): 9–10.
- Gott M, Barnes S, Payne S, Parker C, *et al*. Patient views of social service provision for older people with advanced heart failure. *Health & Social Care in the Community*. 2007; **15**(4): 333–42.
- Jones R. Acute hospital-based palliative care services for the older person. *British Journal of Nursing*. **14**(11): 596-600, 2005.
- Makin W, Finlay IG, Amesbury B, Naysmith A, Tate T. What do palliative medicine consultants do?. *Palliative Medicine*, 2000; **14**(5):405-9.
- Murtagh FE, Addington-Hall J, Higginson IJ. The prevalence of symptoms in end-stage renal disease: a systematic review. *Advances in Chronic Kidney Disease*. 2007; **14**(1): 82–99. (SA-59)
- 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.
- Prail 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.
- Shuster JL Jr. Palliative care for advanced dementia. *Clinics in Geriatric Medicine*, 2000; **16**(2):373-86.
- Stedford 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.
- Xie J, Brayne C, Matthews FE. Medical Research Council Cognitive Function and Ageing Study collaborators. Survival times in people with dementia: analysis from population based cohort study with 14-year follow up. *BMJ*. 2008; **336**: 258–62.

Further resources

- Cicely Saunders : selected writings 1958-2004*. Oxford : Oxford University Press, 2006.
- Help the Hospices* www.helpthehospices.org.uk
- e-lfh: e-Learning for Healthcare* contains a range of online self-learning programmes, including several relating to end-of-life care (e-elca). Registration is required but is free. <http://www.e-lfh.org.uk/projects/e-elca/index.html>
- Future for Palliative Care. Issues of Policy and Practice*. David Clark, ed. Oxford: Oxford University Press, 1993
- Introducing Palliative Care* 4th ed. Twycross R Publisher Abingdon: Radcliffe Press, 2003.
- Oxford textbook of Palliative Care for Children*. Ann Goldman, Richard Hain, Stephen Liben, eds. Oxford : Oxford University Press, 2006.
- Oxford Textbook of Palliative Medicine* 4th ed. Hanks G, Cherny NI, Christakis NA, Fallon M, Kaasa S, Portenoy R. Oxford : Oxford University Press, 2009.
- 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.



15 minute Worksheet

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 and spiritual needs
- Helping patients with reduced hydration and nutrition
- Procedures in palliative care
- Planning care in advance
- Understanding and helping the person with learning disabilities
- The last hours and days
- Bereavement

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www.clip.org.uk