

CLiP

15 minute Worksheet



The last hours and days

5: The death

Introductory level

Produced by
St. Oswald's Hospice
Regent Avenue
Gosforth
Newcastle-upon-Tyne
NE3 1EE

Tel: 0191 285 0063
Fax: 0191 284 8004

This version written and
edited by:

Claud Regnard Honorary
consultant in Palliative Care
Medicine, St. Oswald's Hospice

Sarah Allport, Macmillan Nurse,
Newcastle upon Tyne

Aim of this worksheet

To explore some issues for patients and carers at the time of death.

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- If you think any information is wrong or out of date let us know.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.

Case Study

Michael is a 57 year old man with severe learning disability who lives in a community home with three other men with learning disability. Michael was diagnosed with gastric carcinoma some months ago, but presented too late for treatment. He began to deteriorate rapidly, was smoking fewer cigarettes and had difficulty swallowing his tablets. In the last few days he became extremely weak and unable to move in bed without assistance.

He is now comatose and close to death.

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Death- how it is for the patient

For most patients with advanced illness there is a gentle 'winding down' of the body's systems. Even in cardiac and respiratory failure, sudden, unexpected, dramatic deaths are uncommon. At the end it is more a gentle absence of life, than a sudden presence of death. Peaceful silence is the most obvious feature.

Death- how it is for the carers (from Doyle D, 1994)

Some find it easy to cry, others feel as though they have dried up. Some feel the urge to speak, often to express relief. Others feel it's an anticlimax because, in a sense, the patient 'left' hours or days before.

Many are so numbed with grief that they feel helpless and useless, but they may not admit to this. Some cannot remember names, addresses and telephone numbers. This needs to be understood when it comes to giving information about registering a death- the information may have to be given to another member of the family.

Occasionally a relative or partner has been unable to adjust to the deterioration of the patient and reacts with shock or anger to what is obvious to everyone else. It is rare for such people to be truly ignorant of the facts; it is just that they have not been able to face the terrible reality. Experienced help and support from a palliative care specialist (doctor, nurse or social worker) may be needed.

(Doyle, 1994)

Death- how it is for the professional carer

Awkward is how it feels.

There is an overwhelming feeling to -do something (check the pulse, breathing, move a pillow, make tea)
 -say something (usually something like, "Well, he's at peace now.")

There are no rules, but there are some principles:

- Take your cue from the family or partner- enable them to do it their way.
- Silence is awkward, but is right in the right place (anyway, there's nothing you can say that will make it better).
- If those present want to talk then talk; if they're silent then let them be silent.
- Someone will need to check the patient has died. Don't pronounce death until at least several minutes have elapsed from the last breath since some patients take an occasional breath for several minutes.
- After the death, ask those present if they want to stay, and if so, whether they want to be alone.
- Now go and make that cup of tea!

The arrangements

This gives you more things to do:

- Help the family contact friends and relatives.
- Ask them whether it's to be a burial or a cremation.
- Help them choose an undertaker.
- Explain what's on the certificate.
- If a post mortem is needed, obtain consent and explain the arrangements.
- Explain how to register a death.

The death certificate and post mortems

The death certificate should be filled out by the doctor who saw the patient within the last few days.

The cause of death is what is put down (in Michael's case, 'Carcinoma of stomach'), not the mode of death (so not 'respiratory arrest' or 'coma').

There is no reason to seal the certificate in an envelope; it is better for the relative or partner to see the certificate and have the words on it explained. In some cases the patient or partner asks that the diagnosis is kept from other relatives (eg in AIDS). In this case the prime cause of death (eg. 'Cerebral lymphoma') is put in and there is a box on the back of the certificate which ensures that the registrar contacts the certifying doctor later for the underlying cause.

Post mortems required by law: these are necessary where death is due to industrial disease (eg. asbestosis), injury, neglect, suspicious circumstances, or within the normal recovery time of an operation. A relative's permission is helpful.

Post mortems as a valuable way of obtaining information: a relative's permission is essential and usually it is not difficult to ask if this is done sensitively ('It would help us to examine Michael to find out why he had problems with vomiting'). It needs to be made clear that the relative or partner can refuse.

It is unusual for a funeral to be delayed by a post mortem.

Reflect

Think back to the last patient who died with you present.

NB. If you find this hard because of a difficult personal experience then ask a colleague about their experience.

How did it seem for the patient?

How did it seem for the partner, relative or friend?

How did you feel?

Michael drifts into coma and dies peacefully four days later, with his family at his bed side.

What?

What can you do and what can you say?

Michael's mother asks what is going to be put on the death certificate and is a post mortem necessary.

What?

What do you say?

FURTHER ACTIVITY: The Death

Reflect on a patient who died recently. How did you feel?

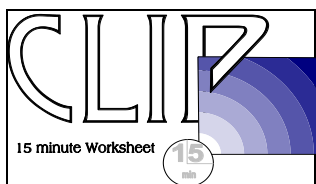
FURTHER READING: The Death

- Bolund C. Loss, mourning and growth in the process of dying. *Palliative Medicine*. 1993; **7**(2): 17-25.
- Chapman CR, Gavrin J. Suffering and the dying patient. *Journal of Pharmaceutical Care in Pain & Symptom Control*. 1995; **3**: 67-90.
- Edmonds P, Karlsen S, Khan S, Addington-Hall J. A comparison of the palliative care needs of patients dying from chronic respiratory diseases and lung cancer. *Palliative Medicine*. 2001; **15**(4): 287-95.
- Ellershaw J, Gambles M, McGlinchey T. (2008) Benchmarking: a useful tool for informing and improving care of the dying? *Supportive Care in Cancer*. **16**(7): 813-19.
- Ellersahw J, Ward C. Care of the dying patient: the last hours and days. *British Medical Journal*, 2003; **326**: 30-4.
- Fragar G. Improving end-of-life care: Listening to voices from the trenches. *Journal of Pain & Symptom Management*. 2001; **21**(3): 249-250.
- Gibbins J, McCoubrie R, Alexander N, Kinzel C, Forbes K. (2009) Diagnosing dying in the acute hospital setting: are we too late? *Clinical Medicine*. **9**: 116-19.
- Hack TF. *Et al* Learning from dying patients during their final days: life reflections gleaned from dignity therapy. *Palliative Medicine*. 2010; **24**(7): 715-23.
- Gomes B, Higginson IJ. Where people die (1974--2030): past trends, future projections and implications for care. *Palliative Medicine*. 2008; **22**(1): 33-41.
- Luddington L, Cox S, Higginson I, Livesley B. The need for palliative care for patients with non-cancer diseases: a review of the evidence. *International Journal of Palliative Nursing*. 2001; **7**(5): 221-6.
- Morita T, Ichiki T, Tsunoda J, Inoue S, Chihara S. (1998) A prospective study on the dying process in terminally ill cancer patients. *American Journal of Hospice and Palliative Care*. **15**(4): 217-22.
- Owen C, Tennant C, Levi J, Jones M. Cancer patients' attitudes to final events in life: Wish for death, attitudes to cessation of treatment, suicide and euthanasia. *Psycho-Oncology*. 1994; **3**(1): 1-9.
- Peterson J. *et al*. What is it so stressful about caring for a dying patient? A qualitative study of nurses' experiences. *International Journal of Palliative Nursing*. 2010; **16**(4): 181-7.
- Pugh EJ, McEvoy M, Blenkinsopp J. Use of the proportion of patients dying on an End of Life Pathway as a quality marker: considerations for interpretation. *Palliative Medicine*. 2010; **24**(5): 544-7.
- Steinhauser KE, Clipp EC, Tulsky JA. Evolution in measuring the quality of dying. *Journal of Palliative Medicine*. 2002; **5**(3): 407-14.
- Wennman-Larsen A, Tishelman C. Advanced home care for cancer patients at the end of life: a qualitative study of hopes and expectations of family caregivers. *Scandinavian Journal of Caring Sciences*. 2002; **16**(3): 240-7.

Further resources

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>

Stedford A. *Facing death : patients, families and professionals* London : Heinemann Medical Books, 1984. (178p. ISBN 0433315504)



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

Available online on
www.clip.org.uk