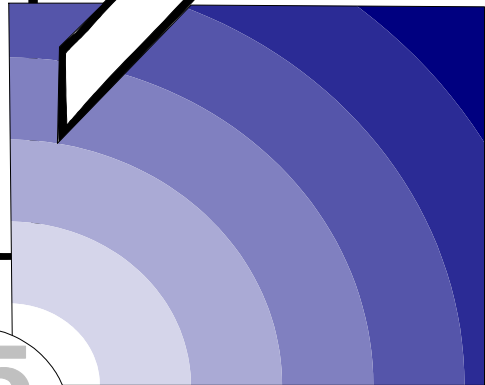
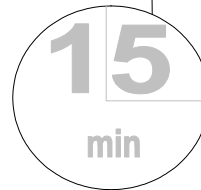


# CLIP

15 minute Worksheet



## The last hours and days

### 1: Adjustments

Intermediate level

<p>Produced by  <b>Coleman Education Centre</b>  <b>St. Oswald's Hospice</b>                  Regent Avenue                  Gosforth                  Newcastle-upon-Tyne                  NE3 1EE</p> <p>Tel: 0191 285 0063                  Fax: 0191 284 8004</p> <p>This version written and edited by:  <b>Claud Regnard</b>                  Consultant in Palliative Medicine                  St. Oswald's Hospice, Newcastle                  Hospitals NHS Trust and                  Northgate&amp;Prudhoe NHS Trust  <b>Janet Jackson</b>, Chaplain                  St. Oswald's Hospice</p> <p><b>Sarah Alport</b>, Senior Nurse  <b>Margeret Younger</b>                  Children's Unit Project Manager                  St. Oswald's Hospice</p> <p>Development of this worksheet was supported by  <b>Help the Hospices for the IMPACT project</b></p>	<p><b>Aim of this worksheet</b>                  To explore the adjustments for the patient and partner, and how to adjust medication in the last hours and days.</p> <p><b>How to use this worksheet</b></p> <ul style="list-style-type: none"> <li>• You can work through this worksheet by yourself, or with a tutor.</li> <li>• Read the case study below, then work on the questions overleaf.</li> <li>• The work page is on the right side, the information page is on the left.</li> <li>• 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</li> <li>• It should take you about 15 minutes. If anything is unclear, discuss it with a colleague.</li> <li>• If you think any information is wrong or out of date let us know</li> <li>• Use the activity on the back page and take this learning into your workplace.</li> </ul> <p><b>Case Study</b></p> <p><b>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.</b></p> <p><b>He has begun to deteriorate rapidly, is smoking fewer cigarettes and now has difficulty swallowing his tablets. He is extremely weak and unable to move in bed without assistance.</b></p>
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### Aims in last 48 hours of life

- *Controlling physical symptoms:* adjustments (psychological or social) are impossible as long as troublesome pain, nausea or breathlessness are present.
- *Give explanations:* lack of information is the commonest cause of problems. Like drugs, information must be titrated to the individual. See the CLiP worksheets on *Breaking Difficult News* and *Collusion and Denial*
- *Anticipate changes:* although it is not possible to anticipate every crisis, planning ahead is essential. For example many patients suffer from bronchial secretions at the end of life and having hyoscine hydrobromide available is sensible
- *Individualise care:* drugs, like information, need to be titrated to the individual.
- *Stop unnecessary drugs:* it is often possible to simplify drug regimes as a patient deteriorates (see below).
- *Continue other drugs by the appropriate route:* the subcutaneous and buccal routes are useful and kind alternatives.
- *Give and take adequate support:* duty demands we provide support, but clinical governance insists we also accept help, advice and support when we are unsure of the situation.
- *Set realistic goals:* goals change as a patient deteriorates, but can still foster hope even if that is now about comfort. Resuscitation issues may need to be discussed- see the CLiP worksheet on *Issues Around Resuscitation*. Working to a clear plan can be helpful- a good example is the Liverpool Care of the Dying Pathway (Ellershaw and Ward, 2003)
- *Explain changes to the partner and family:* they also need as much (or as little) information as they need.
- *Help partner and family understand the changes:* changes are frightening, but it is often comforting to explain the natural course of a death and how gentle it is for most people.
- *Ensure the environment is appropriate:* comfortable and as quiet (or noisy) as they want.
- *Ensure that religious care is offered if wanted:* ask the patient, partner or family if they would like to talk to a chaplain or other spiritual advisor about death and dying.
- *Hydration and feeding:* this has no advantages in the last hours. Very few dying patients want to eat, while most only want sips of water. Encouraging feeding may cause vomiting. Dehydration causing thirst can be helped by hydration, but too much hydration risks increasing bronchial secretions.

### Helping the partner or relative to adjust

- Adjusting to loss is never easy.
- It is common to cope by shuttling back and forth between denial and realism, but this is unsettling for many people.
- The road of life has its potholes and its distant views- looking only at the potholes avoids tripping but lacks interest, whilst looking only at the views means we miss the potholes. Most people need to do both!
- Denial can seem inappropriate at the end of life, but careful listening reveals that most are people being intermittently realistic (eg. "I do hope he can get well enough for that holiday, but he does look an awful lot worse.").
- People need to adjust at their own pace and forcing the pace is unhelpful.
- If you, as the professional, feel at a loss, contact your local palliative care team for help and advice. Nobody has a library of the right things to say. Don't punish yourself for not making things 'better'. Being there, listening and giving explanations when asked will be the most help. Making a difference is what counts.

### Adjusting medication

- First think of Michael's drugs you know you can stop. For example, laxatives can often be stopped. If you have been ensuring a comfortable stool before the deterioration, most people can manage for up to 2 weeks without a laxative.
- Next think of those drugs you know Michael needs to continue:
  - morphine needs to continue, but by a different route. The subcutaneous route is the commonest, but for convenience diamorphine is used since it is very soluble and can be used in low volumes. Divide the total daily morphine dose by 3 to find out the 24 hour diamorphine dose. Some dying patients need a lower dose- reduce if they become more unsettled on switching to diamorphine. See CLiP worksheet on *Changing Opioids*
  - cyclizine would be helpful to control any continuing nausea or vomiting. It can be given in suppository form, or mixed with diamorphine and given subcutaneously (concentrations of cyclizine above 10mg/ml will precipitate).
- This leaves the drugs you might not be sure about:
  - amitriptyline can be stopped if he is deteriorating rapidly since its effects will last at least a further 24-36 hours.
  - dexamethasone is usually stopped in a rapidly deteriorating patient, regardless of the length of previous treatment. In patients deteriorating more slowly, steroids can be safely stopped if the treatment has been for less than 3 weeks, but if they have been taking steroids for 1 month or more it may be necessary to continue the dexamethasone by SC infusion to avoid the 'washed out' feeling of adrenocortical insufficiency.
  - temazepam can be stopped if the treatment has been less than 3 weeks. In many patients, however, treatment has been much longer and a benzodiazepine will need to be continued to avoid agitation due to withdrawal.
  - cigarettes are rarely continued by very ill patients. Beware, however, of agitation due to nicotine withdrawal. This is simply treated by using a nicotine patch.

# Reflect

What do think are the aims of a professional in the last hours and days?

Michael's family are very worried that Michael is not eating and only taking sips of water.

## Write

Before thinking of what to say to his family, write down are the advantages of and disadvantages of hydration and feeding in the last stages of life?

Advantages	Disadvantages

**Q** What do you say to Michael's family?

## Write

What changes would you make to Michael's treatment sheet ?

Drug	Stop? Continue? Change to what drug and dose?
<i>Morphine CR 60mg twice daily</i>	
<i>Cyclizine 50mg three times daily</i>	
<i>Amitriptyline 100mg at bedtime</i>	
<i>Temazepam 40mg at bedtime</i>	
<i>Dexamethasone 8mg daily</i>	
<i>Co-danthrusate 2 capsules daily</i>	
<i>15 cigarettes daily</i>	

## FURTHER ACTIVITY: Adjustments

Think back to the last dying patient you cared for:

-what adjustments did the patient and partner/relative have to make?

## FURTHER READING: Adjustments

### Journal articles

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.

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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.

Higginson IJ. Astin P. Dolan S. Where do cancer patients die? Ten-year trends in the place of death of cancer patients in England. *Palliative Medicine*. 1998; **12**(5): 353-363.

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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.

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.

Seamark DA. Williams S. Hall M. Lawrence CJ. Gilbert J. Dying from cancer in community hospitals or a hospice: Closest lay carers' perceptions. *British Journal of General Practice*. 1998; **48**(431): 1317-21.

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.

### Book resources

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

# CLIP

**Current Learning In Palliative care**

An accessible learning programme for health care professionals

**Fifty seven 15 minute worksheets are available on:**

- An introduction to palliative care (3 worksheets)
- Helping the patient with pain (9 worksheets)
- Helping the patient with symptoms other than pain (11 worksheets)
- Moving the ill patient (2 worksheets)
- Psychological needs (8 worksheets)
- Helping patients with reduced hydration and nutrition (8 worksheets)
- Procedures in palliative care (4 worksheets)
- Understanding and helping the person with alternative communication (learning disabilities) (5 worksheets)
- The last hours and days (4 worksheets)
- Bereavement (3 worksheets) □

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Helping the Patient with Advanced Disease: a Workbook. Regnard C. ed.

Oxford: Radcliffe Medical Press [www.radcliffe-oxford.com](http://www.radcliffe-oxford.com)