

CLiP

15 minute Worksheet



The last hours and days

1: Adjustments

Intermediate level

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Aim of this worksheet

To explore the adjustments for the patient and partner, and how to adjust medication in the last hours and days.

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- If you think any information is wrong or out of date let us know.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

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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 an individualised clear plan is essential.
- *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.

Involving the partner or relative

- 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.
- Clear communication at the individual's pace is crucial.
- 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:*
 - a strong opioid needs to continue, but by a different route- the subcutaneous route is the commonest. Diamorphine has been the traditional choice (conversion = 40mg diamorphine SC/24hrs). Increasingly teams are using morphine injection (conversion = 60mg morphine SC/24hrs). Some dying patients need a lower dose if they become more unsettled on switching to diamorphine or morphine. See CLiP worksheet on *Changing Opioids*
 - cyclizine would be helpful to control any continuing nausea or vomiting. It can be mixed with diamorphine or morphine and given subcutaneously (concentrations of cyclizine above 10mg/ml may 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 for several days.
 - 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 as a once daily SC injection to avoid the 'washed out' feeling of adrenocortical insufficiency.
 - temazepam can be stopped if it was started within the last week. For others, treatment will need to continue to avoid withdrawal agitation by using a midazolam SC infusion (at least 10mg/24hrs).
 - 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 50m three times daily</i>	
<i>Amitriptyline 100mg at night</i>	
<i>Temazepam 40mg at night</i>	
<i>Dexamethasone 8mg daily</i>	
<i>Senna 4 tablets 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.

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.

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.

Jaccoud M. The dreams of dying cancer patients at the end of life. *Psychotherapies*. 1990; **10**(2): 77-84.

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.

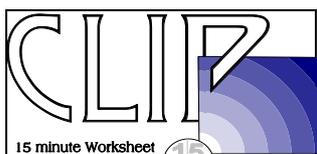
Steinhauser KE. Clipp EC. Tulsky JA. Evolution in measuring the quality of dying. *Journal of Palliative Medicine*. 2002; **5**(3): 407-14.

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.

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-ecla). Registration is required but is free. <http://www.e-lfh.org.uk/projects/e-elca/index.html>

Stedeford 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