CLiP

15 minute Worksheet

15 min

The last hours and days

3: Managing distress

Intermediate 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 learn how to reduce patient distress 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- If you think any information is wrong or out of date let us know.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.

Overnight he has become unsettled and distressed.

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INFORMATION PAGE: Managing distress

Symptoms in the last 48 hours of life

200 patients seen by a community palliative care service had the following problems in the last days of life:

Noisy/moist breathing 56%;	Urinary incontinence/retention 53%;	Pain 51%;
Restlessness/agitation 42%;	Dyspnoea 22%;	Nausea and vomiting 14%;
Sweating 14%;	Jerking/twitching/plucking 12%;	Confusion 9%

Lichter I, Hunt E (1990)

Managing symptoms

Noisy/moist breathing Positional change may be enough to reduce noise; otherwise consider hyoscine butylbromide 20mg SC (less sedating) or hyoscine hydrobromide 400microg SC (more sedating but longer acting). If cardiac failure is the cause consider frusemide 40mg IV or IM. If necessary, use gentle suction.

Urinary incontinence This is likely to reduce in the last few hours and days as oral intake falls. If it persists, consider the use of pads or catheter (indwelling or intermittent), or use sheaths for male patients.

Urinary retention If possible assist the patient to the toilet and maintain privacy. If all else fails consider catheterisation (indwelling or intermittent).

Pain Finding the cause is the key (see the CliP Worksheet on *Diagnosing the Pain*). Disease-related pain does not usually worsen in the last stages of illness, but some new problems may cause pain and each needs a different treatment. Examples are urinary retention (catheterise), colic due to constipation (hyoscine butylbromide 20mg SC), uncomfortable position (re-position, paracetamol PO or PR), infection (antibiotic PO or a single dose of ceftrioxone 500mg SC), and pressure sore pain (pressure relieving mattress).

Restlessness/agitation/confusion Find and treat the cause if possible– it may be related to the above problems, fear or emotional distress (see the CliP Worksheet on *Confusion*). If other measures are inappropriate, consider sedation.

Breathlessness Find and treat the cause if appropriate (see the CliP Worksheet on *Breathlessness*). Consider changing the patient's position, increasing air movement (fan, open windows), oxygen, relaxation, and explanation. Consider drugs to a) reduce any fear and b) reduce the feeling of breathlessness.

Nausea/vomiting Continue antiemetics by the most appropriate route. Where the stomach is distended and the patient continually 'leaks' vomit consider the brief insertion of a nasogastric tube to aspirate fluid and air.

Sweating Keep the patient cool, regularly change bed linen and use cotton nightwear. Involve the family in sponging the patient if they wish.

Jerking/twitching/plucking Exclude causes of confusion (see the CliP Worksheet on *Confusion*). Alternatively the this may be myoclonic jerks due to their opioid, in which case reduce the dose or change opioid. Seizures may need low dose midazolam (2.5-5mg bucally initially followed by 10-30mg/24 hours SC infusion).

Managing an agitated confusion

- **Start with the simple things (not with drugs)**
  Switch on a side light.
  Make sure the environment is quiet.
  Keep visiting strangers to a minimum.
  Explain what is happening to patient, partner and staff.

- **Treat the cause if you can** (see CliP worksheet on *Confusion*).
  Check for any drugs recently started (for adverse effects) or stopped (for withdrawal effects).
  Exclude chest or urinary infections, and exclude a full bladder or rectum.
  Start appropriate treatment if the patient and carer agree.
  The confused patient still has the right to refuse treatment (unless they are harming themselves or others).
  NB: There is no evidence that treating a chest infection lengthens a prognosis inappropriately.
  Hydration might help Michaels' confusion if he is dehydrated.

1) **F** Michael may be frightened and simply may need company. If the agitation is distressing for Michael he may need medication to allow a fuller assessment. Sedation is not the aim, although in severe agitation it may be necessary to use doses that result in some sedation.

2) **T** Nicotine withdrawal is a cause of agitation. If smoking is not an option, then nicotine patches may help.

3) **F** Darkness creates dark areas which can be frightening to a confused person.

4) **F** A patient has the right to refuse treatment, even if the choice does not seem logical. The only exception is the patient who is at risk of harming themselves or others.

5) **F** A chest infection can cause distressing airway secretions, pyrexia, pain and confusion.

Michael carers tell you he gets pain on turning
and has 'moist' breathing that sounds like a rattle

Think of some causes for his pain and for his 'rattle' breathing
How could you mange these?

	Possible causes	Treatment
Noisy breathing		
Pain		

Michael is on the following drugs:
Diamorphine SC (subcutaneous) infusion 40mg daily, cyclizine SC infusion 150mg daily and midazolam 5mg SC as required

Initially settled, one evening Michael starts to become frightened, agitated and suspicious of people

Answer the following questions

1. Start by settling his agitation with sedatives — True — False
2. He might settle if he could have a cigarette — True — False
3. Switching on the light will make things worse — True — False
4. Refusing treatment can be ignored as he is confused — True — False
5. Treating a chest infection is always inappropriate — True — False

FURTHER ACTIVITY: Managing distress

Reflect on the last distressed patient you cared for at the end of life.

- What simple measures were used to ease the distress?

FURTHER READING: Managing distress

Bolund C. Loss, mourning and growth in the process of dying. *Palliative Medicine.* 1993; **7**(2): 17-25.

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

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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)