

## The last hours and days

# 2: Planning the care of the dying patient

Intermediate

**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

### Aim of this worksheet

To understand the principles of planning care for the dying patient

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- If you think any information is wrong or out of date let us know.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

**His community nurse and carers are clear he is entering the last days of his illness.**

v6

## INFORMATION PAGE: Planning the care of the dying patient

Since 2001 the Liverpool Care Pathway had been praised by many national and international organisations as a key tool for the development of best practice in end of life care. However, concerns began to be expressed that it was the cause of poor care of dying patients because of incorrect interpretation of its purpose and intentions. A panel led by Baroness Neuberger in 2013 found no evidence that it hastened death or that pathways were harmful but did find evidence that it was being misinterpreted by some healthcare professionals. Their recommendation was that it should be banned in the UK by July 2014 and it is no longer in use in the UK. It remains in use in a number of countries around the world.

Concerns about planning care in a dying patient include: certainty that the patient is dying; clarity about the patient's wishes regarding treating reversible causes; transparency of communication between professionals, patient, partner and relatives; communication that is enabled by the professional but not driven by the professional; lack of knowledge or understanding of capacity legislation; use of pathways as strict protocols rather than guides; incorrect belief that analgesic and sedative drugs are required in all dying patients; lack of knowledge or understanding about making cardiopulmonary resuscitation decisions; temptation to blame poor care on plans rather than poor training and attitudes.

### True or false answers:

1. **F** The 2013 Neuberger panel did not find any evidence that the LCP hastened death and their academic review was stated that there is no evidence that clinical pathways in dying patients are the cause of poor care
2. **F** A report in 2015 showed that care of the dying was no better.
3. **F** While sometimes this is obvious, it can be difficult, especially in non-cancer patients. Accuracy increases the closer you get to death- the 'horizon effect'.
4. **T** Some patients recover if a reversible cause of their deterioration is found (eg. hypercalcaemia). For this reason all care decisions should be reviewed on a daily basis.
5. **F** There is no evidence that this shortens life or hastens death. Planning for the worse while hoping for the best is not a contradiction but a reality for many.
6. **F** Drugs that might be needed are written up, but if they are not needed, or used only infrequently there is no requirement to start a syringe driver.

### Initial Assessment

This includes goals relating to 1) communication with the patient, partner, relatives and carers; 2) discontinuing any non- essential drugs; 3) prescribing of essential drugs by the non-oral route; 4) prescribing drugs that may be needed; 5) assessment of nutrition and hydration; 6) reviewing current tests and treatments and stopping any that are no longer needed; and 7) ensuring support (emotional, spiritual and social) for patients and their families; 8) frequent clinical review and regular senior assessments

*Choice answers:* all of these should have to be circled!

### Potential symptoms at end of life

These include pain, nausea, vomiting, agitation, respiratory tract secretions and dyspnoea. Unnecessary delays and discomfort can be avoided by anticipatory prescribing of 'as required' medication for these symptoms.

### Care after death

This section guides the multiprofessional team to a) support relatives / carers after death; b) ensuring policies / procedures have been followed regarding last offices (patient care dignity); c) the giving of relevant documentation and information to the appropriate person; d) ensuring the person understands what they have to do next; and e) the appropriate services across organisations have been notified of the patients death.

### What are the advantages of planning care in dying patients?

Planning care enables health care professionals to achieve the best quality of care for dying patients, their partner, relatives and carers during this distressing time and create a lasting memory for relatives and carers.

There is no evidence that a specific care plan for the dying patient is necessary to provide good care and an individualised care plan should be able to adapt whether a patient is dying or not. However, guidance for busy healthcare professionals caring for dying patients is helpful. Since the demise of the LCP many such guides have evolved.

Sadly the reality remains that care of the dying in some settings remains poor.

## Write

Write down your concerns about planning care in a dying patient

True  
or  
false?

- |  |      |       |
|--|------|-------|
| 1. The Liverpool Care Pathway was proven to be the cause of poor care and of hastening death in some cases | True | False |
| 2. Care of the dying has improved since the LCP was banned in the UK                                       | True | False |
| 3. Diagnosing dying is straightforward   | True | False |
| 4. Not all patients go on to die   | True | False |
| 5. Planning care in a dying patient hastens death  | True | False |
| 6. All dying patients must be started on a syringe driver of morphine                                      | True | False |

## Choose

Consider a patient known to be dying

**Ring** which of these have to be considered.

- |                                      |  |                            |
|--------------------------------------|--|----------------------------|
| Discussion with patient and family   | GP informed  | The patient is comfortable |
| Antiemetics written up if needed     | Anti-secretory medication written up for use if needed |                            |
| DNACPR form completed                | Analgesics written up if needed                        |                            |
| Spiritual needs addressed            | Assessed every few hours as inpatient                  |                            |
| Need for hydration & feeding checked | Unnecessary tests stopped                              | Full team review every day |

## Reflect

What issues would you want to consider after the patient has died?

## Reflect

Has your view of the planning care in dying patients changed?

## FURTHER ACTIVITY: Planning the care of the dying patient

Think back to the last patient who died.

- Was their planned in advance and adapted as circumstances changed?
- Was the quality of care excellent, adequate or poor?

## FURTHER READING: Planning the care of the dying patient

Douglas C, Murtagh FE, Chambers EJ, Howse M, Ellershaw JE Symptom management for the adult patient dying with advanced chronic kidney disease: a review of the literature and development of evidence -based guidelines by a United Kingdom Expert Consensus Group. *Journal of Palliative Medicine*. 2009; **23**(2):103 – 10.

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Ellershaw JE, Smith C, Overill S, Walker SE, Aldridge J Care of the Dying: Setting standards for symptom control in the last 48 hours of life. *Journal of Pain and Symptom Management*. 2001; **21**(1): 12 – 17.

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Ellershaw JE Editorial – Care of the dying: what a difference an LCP makes! *Palliative Medicine* 2007; **21**: 365- 386

George R, Martin J, Robinson V. The Liverpool Care Pathway for the Dying (LCP): lost translation and a tale of elephants, men, myopia – and a horse. *Palliative Medicine*, 2014; **28**: 3.

Hockley J, *et al*. The integrated implementation of two end-of-life care tools in nursing care homes in the UK: an in-depth evaluation. *Palliative Medicine*. 2010; **24**(8): 828-38.

Jack B, Gambles M, Murphy D, Ellershaw JE Nurses' perceptions of the Liverpool Care Pathway for the Dying Patient in the acute hospital setting. *International Journal of Palliative Nursing*, 2003; **9**(9): 375 – 381.

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Matthews K. *Et al* Developing the Liverpool Care Pathway for the dying child. *Paediatric Nursing*. 2006; **18**(1): 18-21.

Neuberger J *et al*. *More Car, Less Pathway: a review of the Liverpool Care Pathway*. Crown: London. July 2013.

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Regnard C. The demise of the Liverpool Care Pathway: should we ban the highway code because of bad drivers? *Age Ageing*; 2014; **43** (2): 171-173.

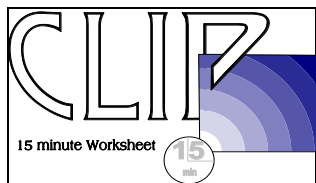
Veerbeek L. *Et al*. Using the LCP: bereaved relatives' assessments of communication and bereavement. *American Journal of Hospice & Palliative Medicine*. 2008; **25**(3): 207-14.

Walker R, Read S. The Liverpool Care Pathway in intensive care: an exploratory study of doctor and nurse perceptions. *International Journal of Palliative Nursing*. 2010; **16**(6): 267-73.

### Further resources

*e-fff: 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.

*One Chance to get it right*. Leadership Alliance for the Care of Dying People. June 2014



**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](http://www.clip.org.uk)