

Foundations in palliative care

A programme of facilitated learning for care-home staff

Pain and symptom management **Participant's workbook**

Name

Supported by



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Macmillan Cancer Relief, registered charity number 261017.
A company limited by guarantee, registered in England, No 2400969.
Registered office: 89 Albert Embankment, London, SE1 7UQ

ISBN 0-9543681-8-5

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Contents

	Page
Workshop 1 Understanding pain in older people	2
Ground rules	2
Module aims	3
Aim of the workshop	3
Programme	3
Notes (session 1.2)	4
Understanding total pain	5
Martha: a case study	6
Reasons for failure to relieve pain	7
Fears about prescribing opioids	8
Next workshop	11
Workshop 2 The principles of pain and symptom management	12
Aim of the workshop	12
Programme	12
Pain chart	13
Pain questions	14
The analgesic ladder	15
Notes (session 2.6)	16
Management of general symptoms	17
Next workshop	22
Workshop 3 Responding to residents' need for pain and symptom management	23
Aim of the workshop	23
Programme	23
Three case studies	24
Characters for role play	26
Useful telephone numbers	27
Notes (session 3.6)	28
Policy statement	29
Next module and workshop	30
Certificate of attendance	31

Workshop 1

Understanding pain in older people

Ground rules

If the ground rules have changed, or you are new to the programme, write the rules here.

1.

2.

3.

4.

5.

6.

7.

8.

9.

10.

Module aims

Workshop 1 Understanding pain in older people

To reflect on the experience of pain from the resident's point of view.

Workshop 2 The principles of pain and symptom management

To understand the treatment of pain and the other common symptoms associated with ageing and dying.

Workshop 3 Responding to residents' need for pain and symptom management

To understand strategies for the management of pain and other symptoms, and how to liaise effectively with other support workers.

Aim of the workshop

To reflect on the experience of pain from the resident's point of view.

Programme

Session 1.1 Introduction	10 minutes
Session 1.2 Pairs activity: the experience of pain	5 minutes
Session 1.3 Feedback	10 minutes
Session 1.4 Discussion: residents' pain and its causes	15 minutes
Session 1.5 Pairs activity: understanding 'total pain'	10 minutes
Session 1.6 Feedback	10 minutes
Session 1.7 Discussion: how do we recognise pain in others	10 minutes
Session 1.8 Discussion: what stops us taking residents' pain seriously?	10 minutes
Session 1.9 Closing remarks	10 minutes
Total	1 hour 30 minutes

Notes (session 1.2)

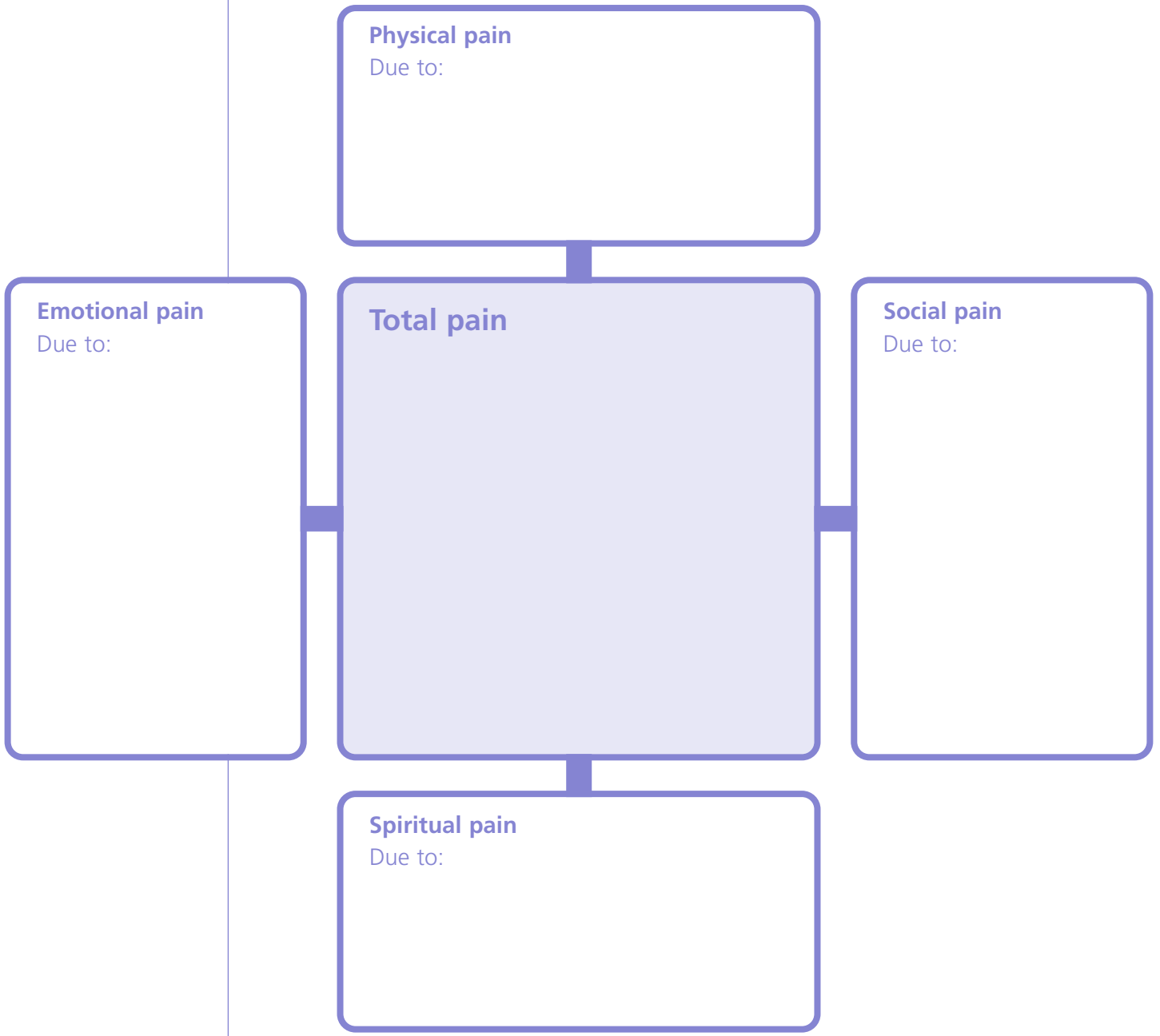
What was the worst pain you have ever experienced?

What did you feel and think when you were in pain?

How effective was the treatment?

Other notes

Understanding total pain



Fears about prescribing opioids

This text includes extracts taken from The Open University *Death and Dying* course (K260), *Palliative care handbook*, which are reproduced by permission of The Open University.¹

Morphine is the most commonly prescribed opioid drug.

There are many prejudices and fears about prescribing opioids which cannot be justified by experience in clinical practice but which have led to patients receiving inadequate pain control. These fears are present in both the professionals and patients. We know that opioids are among the safest strong analgesics we can prescribe and there is no reason to avoid their use early in the illness. The major fears are:

1. Addiction

Patients will become addicted to opioids.

Physical dependence does occur with opioids. This means that if a patient is on a moderate dose of opioid it cannot be stopped suddenly. If it is stopped suddenly then patients will have unpleasant physical side-effects.

Interestingly, such physical dependence occurs with many drugs, for example steroids and diazepam. All patients can stop their opioid, irrespective of the dose, provided the morphine is slowly reduced.

2. Tolerance

I must not start morphine too early in case my patient becomes used to it and the dose will need increasing.

Morphine should not be reserved for the 'terminal phase' of a patient's illness. Morphine should be prescribed for pain early in an illness rather than a whole range of ineffective analgesics.

3. Respiratory depression

I cannot use opioids in frail patients or those with respiratory problems as it precipitates respiratory depression. If patients are given a high dose of morphine then one of the side-effects is that their breathing deteriorates.

Opioids improve breathlessness in patients with lung problems. They do this by reducing ventilatory demand and therefore reducing the sensation of breathlessness. Opioids are used in palliative medicine to control symptoms in patients who are short of breath.

Workshop 2

The principles of pain and symptom management

Aim of the workshop

To understand the treatment of pain and the other common symptoms associated with ageing and dying.

Programme

Session 2.1 Introduction	5 minutes
Session 2.2 Pairs activity: recognising and responding to the need for pain relief	5 minutes
Session 2.3 Feedback	10 minutes
Session 2.4 Discussion: resistance to prescribing strong painkillers	10 minutes
Session 2.5 General information: the analgesic ladder	15 minutes
Session 2.6 Discussion: causes and treatment of other symptoms	15 minutes
Session 2.7 Discussion: management of the common symptoms associated with ageing	25 minutes
Session 2.8 Closing remarks	5 minutes
Total	1 hour 30 minutes

Pain chart¹

Date: _____

When did the pain begin (time)? What was the person doing?	How long did it last?	Where was it?	How severe was it? Rate 1–5 using pain-severity scale. What did it feel like?	What was given for relief?	Did it help? Rate 1–5 using pain-relief scale. Any side-effects?

Pain scales

Pain-severity scale

1	2	3	4	5
Mild	Discomforting	Distressing	Horrible	Excruciating

Pain-relief scale

1	2	3	4	5
No relief	Slight relief	Moderate relief	Lots of relief	Complete relief

Reference

- Adapted from Anne's Cancer Centre (2002). Pain chart. www.annescancer.tripod.com/pain_chart2.html

Pain questions

- What type of pain is it?
- Where is it?
- Is it worse when you move?
- Is it worse at certain times of the day?
- What relieves the pain?
- How do you feel about the pain?
- Is it worse at particular times, such as after you go to the toilet or after you have eaten?

Notes (session 2.6)

Common symptoms that residents experience

Cause of the symptom

Treatment of the symptom

Other notes

Management of general symptoms

This text is based on material used in The Open University *Death and Dying* course (K260), workbook 2, *Caring for Dying People*, and includes extracts that are reproduced by permission of The Open University.¹ The focus of the text is the management of specific symptoms after diagnosis. Without knowing the cause it is difficult to manage symptoms appropriately and effectively. Often a discussion and simple examination of will suggest a cause.

Weakness

Eighty per cent of dying people find that they suffer from feelings of fatigue, lethargy, and weakness. Usually weakness is caused by progressive disease. Weakness is often the first sign that something is wrong.

Many dying people eat little, and if you think the weakness relates to inadequate nutrition, you may decide to ask a dietitian how to stimulate appetite and suggest digestible foods. People nearing death may find persistent weakness frustrating yet be reassured by discussion and explanations. The accompanying despondency might improve if the dying person is helped to discuss these issues and plan positively.²

Dying people who experience weakness often complain about accompanying weariness and boredom. Boredom can be one of the greatest problems for the terminally ill patient and a major cause of 'weariness', but it is often not observed by the doctor and family, who are all so busy. Portable televisions should have remote controls, cassettes should be prepared of favourite music and readings, simple household tasks should be given to the patient (e.g. shelling peas, drying cutlery), and a host of activities within his limited ability should be put within reach.³

Physiotherapists can give invaluable advice about aids and adaptations which can make the most of a dying person's remaining strength.

Dyspnoea (breathlessness)¹

Experiencing breathlessness can be very frightening and unsettling for all concerned. Dyspnoea (pronounced disnee a) is a common symptom following heart and lung disease. Feelings of breathlessness can both be exacerbated by anxiety as well as create anxiety.

So how can dyspnoea be alleviated? The usual treatments include both drug therapy and other methods. If you think the breathlessness is caused by anxiety, relaxation therapy may help teach breathing control and reduce hyperventilation. Low doses of diazepam (Valium) can also help people to relax.

Nebulisers are useful for people with breathing difficulties.

You might find that changing the environment improves dyspnoea. Helping the person sit upright in loose clothing, cooled by a fan in calm surroundings may alleviate symptoms. Alternative therapies might include counselling, facilitating the expression of fears, listening to relaxation tapes, or being hypnotised.

Loss of appetite (anorexia)

In dying people, anorexia has a number of causes, some of which relate to the disease or diseases. Other causes reflect the psychological status of the dying person, such as a fear of vomiting, an aversion to the quantities of food or the way it is presented to them, depression, or anxiety.

Many people nearing death lose interest in food. Carers often worry when food is refused. Many people believe that death follows starvation, despite the fact that many hunger strikers live for months.⁴ A dying person acknowledging that death is inevitable and that food creates discomfort may be making an informed decision not to eat except when hungry. There are also cultural variations here – some Muslims choose to fast as they approach death.

Carers, both professional and informal, who feel that food is fundamental to proper care should be encouraged to acknowledge that by abandoning force feeding they are not being neglectful. On the contrary, carers may recognise that they are offering choice. This may be the only aspect of their lives over which dying people feel they have control. When someone is dying they do not have the same nutritional needs of food – although they may need supplements to prevent other symptoms.

Sometimes a solution for anorexia can be found in trying to improve the dying person's quality of life in general and, in particular, acknowledging that eating normal-size meals might be inappropriate. Small more frequent meals of favourite dishes may be preferred and you might encourage eating for pleasure rather than 'to build up strength', which might be unrealistic and irritating.

Nausea and vomiting

Nausea and vomiting can be caused by many drugs, including opioids, digoxin, and antibiotics. Non-drug-related causes may be metabolic, such as high levels of calcium, gastric problems, such as inflammation or ulcers, bowel obstruction due to growth or constipation, and less commonly problems with the inner ear, such as vertigo. People often find the symptoms of nausea more distressing than vomiting. Effective treatment of nausea and vomiting may require investigations to establish the cause.

Sometimes it is easy to establish the cause – it might be the response to a drug or an additional condition such as hypercalcaemia (increased circulating calcium levels). When the cause is amenable to an anti-emetic (anti-nausea drug) then it is usually possible to control the sensations of nausea and

vomiting even in people with advanced disease. Certain anti-emetics exacerbate symptoms so prescribing has to be particularly cautious. Sometimes more than one anti-emetic will be necessary to control symptoms.

Constipation

Constipation is defined as the passage of small hard faeces infrequently and with difficulty. Constipation is a major problem for dying people. As a known side-effect of opiate treatment it should be prevented. Although it is probably the most common problem dying people face, it is often ignored, causing tremendous discomfort and frustration. Unfortunately, many people assume constipation is inevitable if large quantities of bulk food are not eaten. It is a principal cause of vomiting and a major factor in producing abdominal discomfort, lethargy, anxiety about painful or exhausting defecation, anorexia, colic, and even confusion. Dying people complaining of constipation will want it resolved, and may have to undergo rectal examinations and be treated with laxatives. Sometimes constipation is so severe that the fluid contents of the bowel leak past and produces overflow incontinence. There are four groups of laxatives which act in two ways, either by stimulating the bowel to expel its contents, such as senna, a colonic stimulant, and lactulose, an osmotic laxative, or by increasing the bulk, such as bran and docusate sodium, which softens by allowing water to penetrate hard faeces.

Confusion

This is quite a common symptom especially in older people. The term confusion implies loss of touch with reality and is used to refer to a range of symptoms including disorientation in time and place, various sorts of inappropriate behaviour, loss of memory, hallucinations, incoherent speech, and paranoia.

The term also includes temporary states resulting from severe constipation, or fluctuations due to arteriosclerosis, or it may be degenerative due to Alzheimer's disease or be due to secondaries, treatment, or complications in people with cancer. Confusion in dying people can be made worse by distress or other people's responses to them. One should attempt to ascertain the cause of the confusion before deciding to rule out treatment.

Many of the conditions that give rise to confusion are treatable; therefore, it must not be assumed that little can be done other than to sedate the patient. However, if there is no reversible cause, then sedation may be appropriate.

Confused residents are often very frightened since they are usually at least partly aware of what is happening to them and fear they may be going mad. Drowsiness can result in vivid memories or even hallucinations that seem real. It is not surprising that this is distressing to patients and results in them behaving as if terrified. In addition, confused and agitated patients are

disturbing to other people who do not know how to react to them and consequently feel helpless and frightened.

There are a number of ways to manage confusion. Sedation is often used, but there are alternatives. As confused people have lost their sense of reality and control over their lives, you may attempt to reacclimatise them to their surroundings and explain their current state. Also, it is important for a confused person to still feel loved and accepted, and trying to reorient them might make matters worse.

Some confused people become agitated and hyperactive, even aggressive. They could pose a danger to themselves and to others. In caring for a confused dying person, you may find yourself in a dilemma, trying to ensure that their self-respect and control are retained, whilst ensuring that they are not in danger. You might reluctantly resort to sedation as the short-term solution; sometimes in preterminal confusion, heavy sedation is the only way of containing the dying person's distress.

Confusion can be caused by drugs, a high temperature, withdrawal of alcohol to which someone might be addicted, brain disease and, in extreme old age, when someone is moved to a strange place.

Mouth problems

Good mouth care is essential to the well being of debilitated patients

Mouth problems can be caused by:

1. Poor oral hygiene
2. Poor nutritional state, dehydration, drowsiness, anaemia
3. Oral thrush and other infections
4. Some drug treatments that dry secretions

Treatment

1. Review medications causing dry mouth/ulceration
2. Treat oral infections
3. Give regular mouth care especially after food and milky drinks
4. Brushing
5. Vitamin C (ascorbic acid) 1g effervescent tablet – allow a quarter or a half of one tablet to effervesce on coated tongue
6. Sips of iced water

References

1. The Open University. *Caring for Dying People*. Workbook 2, course K260. Milton Keynes: The Open University, 2000;42–5.
2. Lichter I. Some psychological causes of distress in the terminally ill. *Palliative Medicine* 1991;5:138–46.
3. Doyle D. The provision of palliative care. In: Doyle D, Hanks G, MacDonald N, eds. *Oxford textbook of palliative medicine*, 2nd ed. Oxford: Oxford University Press, 1998;41–54
4. Stedeford A. *Facing death*. Oxford: Heinemann, 1984.

Workshop 3

Responding to residents' need for pain and symptom management

Aim of the workshop

To understand strategies for the management of pain and other symptoms, and how to liaise effectively with other support workers.

Programme

Session 3.1	Introduction	5 minutes
Session 3.2	Small-group activity: a palliative-care approach	25 minutes
Session 3.3	Feedback	10 minutes
Session 3.4	Small-group activity: providing pain and symptom relief for dying residents (role play)	15 minutes
Session 3.5	Feedback	10 minutes
Session 3.6	Discussion: improving the care of dying residents	15 minutes
Session 3.7	Closing remarks	10 minutes
Total		1 hour 30 minutes

Three case studies

Sally

Sally is an 89-year-old resident of the Harrod House Nursing Home, where she has lived for 12 years. She chose to move to the home following an illness shortly after her husband died. She has no living children (she had a stillborn child). Sally had lots of close friends and visitors, and often went out with them. Her niece was like a daughter to Sally and, when both she and Sally's sister died in quick succession, Sally's world began to seem very cold and lonely. Her own physical deterioration added to her loss of interest in living and her wish to die.

Harold

Harold is a 70-year-old resident of the Ridings Nursing Home. He was admitted following a stroke 9 months ago. He has difficulty swallowing and no longer enjoys his meals. His main symptom is the pain from muscle contractions along his paralysed side. The pain is particularly bad at night and it keeps him awake and leaves him exhausted during the day. His feet and ankles are swollen and painful, and movement is very difficult. Harold is often tearful, especially when his family visits.

Harold made good progress in hospital. He and his wife expected that his progress would continue and that he would be able to return home. This makes it harder for him to cope with his feelings of hopelessness and his continued deterioration.

Poppy

Poppy is 90 years old. She has suffered from rheumatoid arthritis for the past 20 years. She takes paracetamol but finds that it makes her drowsy and resists taking it until the pain is severe. At night she takes sleeping tablets but their effect only lasts for a few hours and she wakes restless and anxious at around 3am. Poppy calls the night staff regularly and they are frustrated by her demands.

Following a severe bout of flu, Poppy had bronchitis and stopped eating. She now spends most of her days in bed. Her arthritic pain is becoming unbearable and she says that she feels that she is waiting to die.

Characters for role play

Mary: Macmillan nurse

Mary is a Macmillan nurse who works locally. She sometimes attends residents who have been referred to her. Anyone can make a referral, but she mostly attends patients who are dying from cancer or motor neurone disease. She has a full caseload but is happy to be consulted about residents' specific needs.

Lesley: matron

Lesley has been the head of the home for 5 years. She did some nurse training 20 years ago but did not qualify. She believes that all residents are entitled to the very best care, particularly when they are dying. Lesley lives close to the home and is often on call when a resident is ill.

Dr Brown: GP

Dr Brown has visited the residents of the home for 30 years and is due to retire next year. He has a good relationship with the staff and knows most of the residents well. He has not done any palliative-care training and relies upon the local hospice to support his patients with cancer. He believes that morphine should be administered only in the last few days of life and that each of the doses must be individually prescribed. He does not believe in a lot of intervention when residents are clearly dying.

Mavis: senior care assistant

Mavis is a senior care assistant who has worked in care homes for the last 15 years. She enjoys her work very much and likes nursing care, which has become an increasing part of her role. Mavis believes that the residents' quality of life is very important and works hard to look after them and respond to their needs.

Esther: resident

Esther is 100 years old and lives in a small residential home called The Willows. As well as having left-sided paralysis from the stroke she suffered 10 years ago, she is also totally deaf and blind. It is therefore very difficult to communicate with her, and no one is sure about her needs. She does, however, seem cheerful most of the time.

Useful telephone numbers

Local palliative-care services:

Person to speak to:

Other healthcare services might include:

Other non-healthcare services might include:

Bereavement counsellor:

Local church:

Local temple:

Local mosque:

Local synagogue:

Any others?

Notes (session 3.6)

What can you do well?

What needs to be improved?

What could you ask other professionals to do?

Who else could help in the care of dying resident?

Other notes



Certificate of attendance

A programme of facilitated learning for care-home staff produced by
Macmillan Cancer Relief and The Open University

This is to certify that

successfully completed

Module 3 Pain and symptom management

on:

Signature:

Position:



Additional copies of the workbooks, CDs and participant flyers can be ordered. Call the Macmillan Resources Line on 01344 350310 or order online www.professionalresources.org.uk/macmillan



Macmillan Cancer Relief works with the NHS and others to provide people who have cancer, and their families, with expert medical care, and with emotional and practical support, from the point of diagnosis onwards, in order that they may carry on living their lives despite cancer.

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