

## Foundations in palliative care

A programme of facilitated learning for care-home staff



# Pain and symptom management

Facilitator workshop guidelines

Supported by



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# Programme

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## Workshop 1 Understanding pain in older people 1 hour 30 minutes

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

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## Workshop 2 The principles of pain and symptom management 1 hour 30 minutes

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

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## Workshop 3 Responding to residents' need for pain

**and symptom management 1 hour 30 minutes**

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

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# General facilitator preparation

- Ensure that all participants have successfully completed module 1
- Familiarise yourself with all three workshops in this module
- Make sure that all the participants know the date, time, and place of the first workshop
- Read the facilitator texts for each workshop and the further reading given at the end of the module
- On the day, check that the room is ready and that there are enough chairs, and that they are set out in a semicircle or other informal arrangement
- Check that refreshments are available, if appropriate
- Check the equipment (flipchart, pens)
- Make sure that you will not be interrupted – put a sign on the door, if necessary ('Training in progress')

## Workshop 1

# Understanding pain in older people

## Aim

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

## Facilitator preparation

Before the workshop you will need to:

- Remind participants of the date, time, and place of the workshop, and ask them to bring a pen for making notes
- Study the facilitator guidelines and the following facilitator texts:
  - Facilitator text 1.1 (*Principles of pain management*), which addresses the principles of the palliative-care approach to pain, the fears that people experience about pain, and pain management
  - Facilitator text 1.2 (*Pain and symptoms*), which is a diagram that illustrates the different dimensions of pain
- If necessary, make notes for the activities on the flipchart – keep them simple and clear
- Make sure that you have enough copies of the *Participant's workbook* for module 3
- Bring the ground rules agreed in module 1

## Facilitator guidelines

### Session 1.1

10 minutes

#### Introduction

Welcome participants and, if necessary, introduce yourself and ask them to introduce themselves to the group.

Display the ground rules agreed in module 1. Although everyone in the group will have completed module 1, they may not have done so together. Therefore, you may need to explain that the ground rules were agreed by another group and that they can be changed. Ask participants if they are happy with the ground rules and if they want to make any changes. This will give everyone a chance to contribute to the ground rules for this module. If participants agree new ground rules, ask them to write them down on p. 3 of their workbooks. You will need to keep the new ground rules to display in

workshops 2 and 3.

Direct participants to p. 4 of the workbook and explain the aims of the workshops in this module, which are:

- Workshop 1 – to reflect on the experience of pain from the resident's point of view
- Workshop 2 – to understand the treatment of pain and the other common symptoms associated with ageing and dying
- Workshop 3 – to understand strategies for the management of pain and other symptoms, and how to liaise effectively with other support workers

Direct participants again to p. 4 of the workbook and run through the programme and timetable for the workshop. Explain that participants will be working in pairs and small groups during the workshop, as well as taking part in discussions with the whole group.

There will be opportunities to do tasks between workshops that will help participants relate their workshop studies to the needs of residents. At the end of this module, there will also be an opportunity to write a policy statement on pain and symptom management for the care home.

### **Pairs activity: the experience of pain**

#### **Session 1.2**

5 minutes

Ask participants to pair up with the person sitting next to them and discuss the worst pain they have experienced and its treatment. Ask them to consider:

- Their feelings and thoughts
- The effectiveness of treatment

If they wish to make notes, they can do so on p. 5 of the workbook.

### **Feedback**

#### **Session 1.3**

10 minutes

Ask each pair to call out the examples and the feelings and thoughts that emerged from their discussions, and their thoughts about the effectiveness of treatment. Summarise the responses on the flipchart. Specific examples of pain that might be mentioned include pain associated with illness – chronic conditions, such as back pain, and acute conditions, such as toothache and childbirth. Feelings and thoughts associated with pain include: fear, inability to tolerate the pain, agitation, stress, irritability, depression, and despair.

### **Teaching points**

Focus the feedback discussion on:

- The difficulties inherent in tolerating pain and the fact that some types of pain are more easily tolerated than others
- The fact that knowing the cause of the pain reduces its associated fear
- The effect of emotions on the experience of pain



## Session 1.4

15 minutes

- The effect of different pain thresholds, past experience of pain, and the type of pain
- The need for someone to take the pain seriously
- The judgements people make about the ability of others to tolerate pain
- The need for fast and effective pain relief

### Discussion: residents' pain and its causes

Keep notes from this activity to use again in workshop 2 (session 2.7).

Ask participants to call out the types of pain experienced by residents and the causes, if known.

#### Discussion points

Participants will probably mention several different types of pain and a range of causes, such as:

- Pain associated with immobility, often caused by arthritis
- Pain associated with stress, such as headache
- Pain associated with indigestion
- Pain associated with cancer
- Pain with no apparent cause

#### Teaching points

The following points are based on facilitator text 1.1 (*Principles of pain management*):

- Everyone has a different pain threshold that changes according to mood, previous experience of pain, and the type of pain. Fear usually increases pain dramatically
- Some types of pain are more manageable than others. If we know that we are going to recover then we can put up with pain better than if we know that we will not recover
- Pain can occur in different parts of the body. Older people, for example, might have several different types of pain that affect different parts of the body
- Acute pain, such as chest pain or the pain caused by a fractured hip, is difficult to ignore and requires immediate pain relief
- Chronic pain, such as that caused by arthritis or persistent headaches, is more likely to be described as discomfort rather than pain. People are able, to some extent, to adjust to chronic pain, although they may be depressed and withdrawn

To complete the discussion, raise the following question: if residents want their pain relieved, do care-home staff have a duty provide pain relief? If the care home supports the principles of palliative care and already provides

high-quality care, the answer must be a resounding 'yes'. The steps care-home staff can take to provide effective pain relief is the subject of the remainder of this module.

### Pairs activity: understanding 'total pain'

#### Session 1.5

10 minutes

Direct participants to p. 6–7 of the workbook (*Understanding total pain*, and *Martha: a case study*), and ask participants to pair up. Use as an example for this exercise either a particular resident with whom all the participants are familiar or Martha. If you are using the case study provided, give them a few minutes to read it through.

Ask each pair to list the factors that influence pain and contribute to its intensity in the boxes on the diagram. Use examples from facilitator text 1.2 (*Pain and symptoms*) to demonstrate what you expect them to do. The completed diagram given in facilitator text 1.2 is based on Martha's case; the group will probably suggest a variety of different factors in each dimension of pain if they discuss a resident they know.

Participants may not understand, for example, the term 'social pain' and may therefore need to be steered towards thinking about the resident's friends and family, financial security, home, and community; similarly 'spiritual pain' might encompass concerns about existence and the meaning of life. Other concerns, such as feeling a burden might be classified as both spiritual and emotional pain.

It is less important that participants complete the handout correctly than they think through and recognise the different dimensions of pain.

### Feedback

#### Session 1.6

10 minutes

Keep the flipchart notes from this session to use in session 2.7.

The way that you manage the feedback from the pairs activity will depend on how many pairs are present:

- Four pairs – ask each one to focus on one of the four dimensions of total pain
- More than four pairs – restrict the responses to one from each pair until all of the dimensions have been covered
- Two or three pairs – ask each pair to cover more than one dimension of pain. Ensure that everyone has an opportunity to contribute and that one pair does not dominate and leave the others with nothing to add

### Feedback points

You might expect participants to mention the following points, which are based on Martha's case:

- Physical pain – pain from passing urine and secondary loss of appetite
- Emotional pain – Martha is depressed but she is also likely to be afraid of

learning her diagnosis

- Social pain – Martha's loss of independence and, possibly, a feeling of shame as a result of the offensive-smelling discharge
- Spiritual pain – fears of the unknown

### Teaching points

Finally, emphasise that pain is not an event experienced in isolation. Neither is it a purely physical sensation. Pain affects and is affected by many dimensions of life. The best way to understand and treat pain is therefore to see it in its total context.

### Discussion: how do we recognise pain in others?

Ask participants to tell you how they recognise residents' pain.

#### Discussion points

You might find it helpful to sort the responses into the following categories:

- Information or signals from residents (either given spontaneously or in response to being asked)
- Information from family and friends
- Information from other residents
- Observation (expression, movement, changes in behaviour, such as withdrawal, depression, or loss of appetite)

Remind participants that an important part of their role is to evaluate the effectiveness of pain-relief techniques; their ability to recognise residents' pain is therefore essential.

### Discussion: what stops us taking residents' pain seriously?

Direct participants to p. 8 of the workbook (*Reasons for failure to relieve pain*) and ask participants to answer the following questions:

1. What stops people expressing pain?
2. What stops us listening to others in pain?

While the first question is straightforward, the second could raise issues about practice that participants find difficult to express. The table will help them identify common problems.

#### Discussion points

Focus the discussion on each question in turn. Mention the following points if participants do not.

Question 1:

## Session 1.7

10 minutes

## Session 1.8

10 minutes

- Fear of being a nuisance
- The assumption that nothing can be done
- Being used to being in pain and seeing it as part of getting old
- Fear of taking strong painkillers
- Fear of the cause of the pain
- Past experience of mentioning pain and nothing being done
- Not being asked about pain

#### Question 2

- Too busy
- Not knowing how to respond or help
- Past experience of inadequate support
- Resident already receiving pain relief
- Any or all of the points from the list on the handout

#### Closing remarks

### Session 1.9

10 minutes

- Thank everyone for taking part in this intensive workshop
- Point out that the workshops will help them build on their life skills and experience
- Ask participants to read p. 9–10 of their workbooks (*Fears about prescribing opioids*) before workshop 2
- Also, ask participants to consider residents' pain and how it is relieved, and to bring some examples to the next workshop (space is provided on p. 10–11 of the workbook)
- Agree the date, time, and place of the next workshop, and ask participants to write the information in the box provided on p. 12 of their workbooks. Remind them that it will address the principles of the management of pain and other symptoms in greater detail
- Finally, suggest that participants record their thoughts about the workshop in their workbooks (p. 12) and how it might affect their practice, and remind them to bring their workbooks to the next workshop

## Principles of pain management

This text includes extracts taken from The Open University *Death and Dying* course (K260), workbook 2, *Caring for Dying People*, which are reproduced by permission of The Open University.<sup>1</sup>

Not all dying people experience excruciating pain. For those who do, it is very distressing and can be frightening. Some people experience more than one pain at a time and each needs to be explored in relation to the other.

Medication can alleviate most pain but there are a small number of people whose pain does not respond to drugs. For them the experience can be very distressing. Most dying people and their carers are keen to remove physical suffering whenever possible as demonstrations of pain can be extremely distressing for all concerned. Other problems, such as anxiety, depression, and insomnia, may be caused by pain or alternatively may contribute to what is seen as physical pain.

When someone is dying, any type of pain can be very significant and overwhelming. It is therefore very important not to ignore what may appear to be a trivial symptom. The following serve as useful guidelines:

- Treat patients/residents as persons
- Deal with all their problems – physical, psychological, social, spiritual, or sexual
- Recognise the interactions between different aspects of the resident's/patient's illness
- Treat appropriately
- Give the patient/resident and/or his or her 'family' as much control, independence and choice as possible
- Provide support not just for the resident/patient but also for the 'family', both during the illness and after the person's death. Dying people must be seen in the context of their 'family'. The 'family' is all those who are important to the resident, and may include their relatives, carers, friends, pets, and so on

Residents with chronic and multiple illnesses are often weak and debilitated and therefore prone to many problems such as chest infections, pressure sores. They are also prey to the usual minor illnesses and discomforts that we all experience in our daily life. Although a problem may seem trivial, for example a toothache or an overgrown toenail, it may represent a major source of discomfort and distress in a patient who has very advanced disease. The mainstay of good palliative care is expert symptom management, enabling the person to be as comfortable as possible and hence gain the greatest benefit from what remains of their life.

Psychological problems can often cause physical symptoms in their own right (for example, loss of appetite, sleeplessness), and can also exacerbate problems that already exist (for example, pain, nausea). In assessing each

symptom the contribution of any underlying psychological problem must be taken into account.

Clinical depression occurs quite frequently in people with advanced disease. Milder forms may be dealt with by counselling and support alone but some people may require treatment with drugs. Depression is often confused with despair. Despair is not a clinical entity with defined criteria like clinical depression. It arises when a person loses hope and is best managed by counselling and support.

Anger is common in people with a terminal illness. Quite naturally, dying people might resent the loss of their ability to achieve the goals they have set themselves in life, and the apparent unfairness that this should happen to them. Frequently the dying person is angry about the illness but finds it difficult to express this and therefore consciously or subconsciously displaces their anger on to people whom it is safe to do so, for example a relative, medical carer, nurse, etc.

Anxiety arises from the many fears that dying people may have. Common fears are:

- Fear that their symptoms will not be controlled; this is especially true of pain
- Fear of the process of dying. Many people fear that the process of dying will be painful and unpleasant. Others are frightened that they will die alone
- Fear of death itself. They may fear that they could be buried alive or there may be fears of retribution in an after-life
- Fear associated with uncompleted tasks, for example a will that has not been made and what the consequences of this might be; a relative that they have not seen for a while and may never be able to see again
- Fear of loss and separation. People who have life-threatening illnesses experience many losses. They may lose control of their physical or mental functions by, for example, becoming incontinent or confused. This loss of dignity is a major problem which many patients have to come to terms with
- Fear of altered body image. Older people might have got used to the gradual changes in their body as a result of ageing, but sometimes this also serves as great source of loss and sadness

Social problems can be a source of great distress to residents and their families. Concerns about money and home can often be dealt with practically by someone with appropriate knowledge, such as a social worker.

Spiritual suffering can contribute to the resident's experience of their physical problems. It is important to distinguish between religion and spirituality. A religion is a particular system of faith and worship. Spirituality is the part of a person that is concerned with ultimate ends and the search for the meaning of existence. Spiritual anguish may well be due to residents having difficulties

with their religious beliefs in the face of death. They may feel that God has deserted them. But people with no religious needs or beliefs may also experience inner turmoil as they approach death and search for meaning within their current illness. Helping the resident to resolve these anxieties involves establishing a trusting relationship within which experiences can be shared. It is for the resident to choose with whom they will establish this relationship, not for someone to be imposed upon them.

To achieve effective pain control all the above problems must be dealt with. Enabling residents to participate in decisions about the management of their problems allows them to regain some degree of control, independence, and choice in a situation where they may feel at the mercy of outside advisers. Managing your own pain or someone else's tends to be equated with relieving pain (drug technology) rather than addressing other factors, such as handling the expression of pain and responses to pain. In addition to handling the expression of pain, one also might be attempting to minimise or prevent pain – in palliative care the goal might be to reduce current pain to a manageable level, or eliminate it for those who prefer to be free of pain even if this dulls sensation or reduces alertness.

Some dying people have to endure pain, and may need help to come to terms with this, while others, particularly Hindus and Buddhists, choose to endure it. Others may express feelings of pain or distress out loud when praying, for example a Muslim calling on Allah. Carers need to assess their own responses to someone they believe is in pain and is being (in the carer's estimation) either excessively expressive or unnecessarily stoic. The way carers respond to the dying person's pain may influence the pain relief offered and inhibit the dying person from disclosing pain. It is therefore important to recognise that each individual has particular expectations of pain and how this should be expressed.

Carers should not wait for complaints of pain but enquire regularly as well as observe: patients in chronic pain do not always look in pain. Clues lie in which drugs have failed, whether sleep is disturbed and whether activity is limited. Some people prefer to be asked about 'discomfort' rather than 'pain'. Friends and carers can also sometimes provide information about pain.

Palliative specialists emphasise careful assessment of the cause and nature of pain, which usually has a physical base.

As 80% of people with far-advanced diseases have pain in more than one place and 34% have more than four separate pains, it may be difficult to establish the cause.<sup>2</sup> It is advisable to take a careful history, noting:

- The site of pain and any radiation
- The type and severity of pain
- When the pain started and any subsequent changes
- Factors that increase the pain and factors that decrease it

Physical examination often confirms the diagnosis. If it is felt that the

outcome of X-rays, scans or other investigations will point to a more effective treatment, some dying people and carers might feel it is worth the discomfort to undergo them.

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## References

1. The Open University. *Caring for Dying People*. Workbook 2, course K260. Milton Keynes: The Open University, 2000;30–35.
2. Regnard C, Davies A. *A guide to symptom relief in advanced cancer*. Manchester: Haigh and Hochland Ltd, 1986.

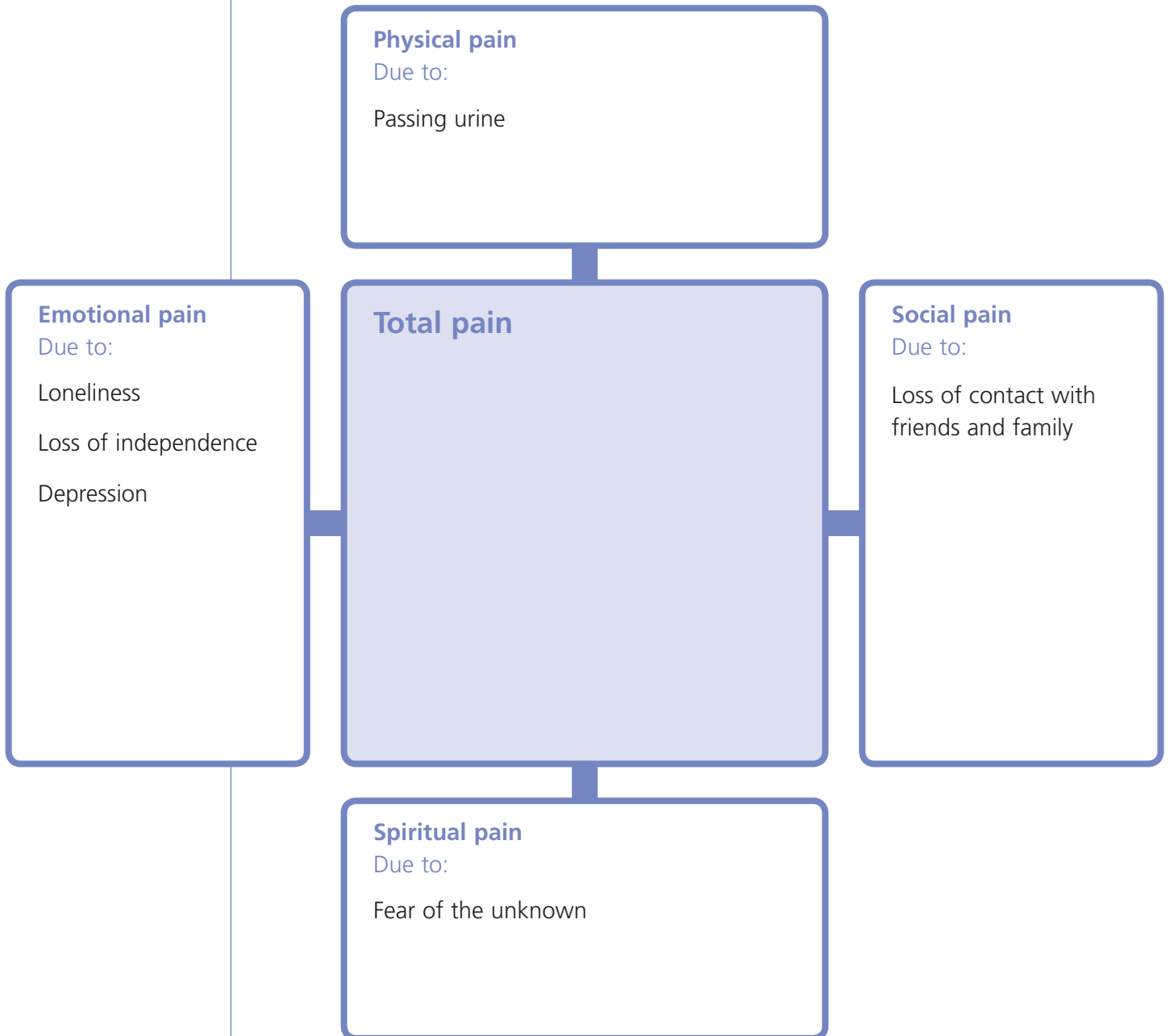


Facilitator text 1.2

# Pain and symptoms

The diagram below illustrates the different dimensions of pain that contribute to total pain. It is based on work by Twycross and Lack.<sup>1</sup> The information in the boxes is based on Martha's case (p. 7 of the *Participant's workbook*).

## Total pain



## Reference

1. Twycross RG, Lack SA. *Symptom control in advanced cancer*. Edinburgh: Churchill Livingstone, 1983;33.

## Workshop 2

# The principles of pain and symptom management

## Aim

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

## Facilitator preparation

Before the workshop you will need to:

- Remind participants of the date, time, and place of the workshop, and ask them to bring their workbooks and a pen
- Study the facilitator guidelines and the following facilitator texts:
  - Facilitator text 2.1 (*Pain and symptom management*), which provides information on the understanding and assessment of pain
  - Facilitator text 2.2 (*Fears about prescribing opioids*), which explodes some of the myths surrounding morphine
  - Facilitator text 2.3 (*Using drugs for the treatment of pain (analgesia)*), which explains how to administer different types of analgesics in accordance with World Health Organisation (WHO) recommendations
  - Facilitator text 2.4 (*Principles of symptom management*), which provides a palliative approach to symptom management
  - Facilitator text 2.5 (*Management of general symptoms*), which explains the causes of common symptoms associated with dying and suggests how to manage them
- You will also need to study further reading 1 (*Withdrawing versus withholding treatment*) at the end of the module
- If necessary, make notes for the activities on the flipchart – keep them simple and clear
- Bring the agreed ground rules

# Facilitator guidelines

## Session 2.1

### Introduction

5 minutes

Welcome participants. Direct them to p. 13 of the workbook and explain the aim of this workshop, which is to understand the treatment of pain and the other common symptoms associated with ageing and dying.

Display the agreed ground rules.

Direct participants again to p. 13 of the workbook and run through the programme and timetable for the workshop. Reiterate that, like the other workshops, this one will require participants to take part in work in pairs and in group discussions, although this workshop includes more teaching sessions than the last one.

## Session 2.2

### Pairs activity: recognising and responding to the need for pain relief

5 minutes

Ask participants to pair up and consider the examples they have collected since workshop 1 (see session 1.9, p. 10–11 of the workbook). Ask them to talk about how they know when residents' pain is relieved. The aim is to focus them on the importance of the assessment and treatment of pain.

The topic of the assessment of pain was raised in workshop 1 (facilitator text 1.2 (*Pain and symptoms*) and workbook p. 7 (*Martha: a case study*)) in terms of the recognition of different types and causes of pain. The term 'assessment' may, however, be unfamiliar to the group and may require explanation.

## Session 2.3

### Feedback

10 minutes

Ask each pair to call out examples of residents' pain, pain-relief techniques, and the signs that the pain is relieved. Summarise the responses on the flipchart. The discussion could produce a variety of responses, particularly if the group includes staff from different care homes. The responses will vary according to the specific needs of residents and the type and extent of support staff receive from GPs and other healthcare professionals. Steer the group towards a discussion of the assessment of pain, rather than a discussion about the support they receive.

### Teaching points

The following points summarise facilitator text 2.1 (*Pain and symptom management*). Present them if they are not raised in the feedback discussion:

- The most important aspect of understanding and recognising pain is that there are no absolute measures, and that the person who is in pain (and no one else) is the expert on their pain

- Evidence from studies in hospital patients shows that, despite recent breakthroughs in pain management, nurses (and doctors) underestimate the extent of pain experienced by patients. Consequently, patients suffer unnecessarily

Care-home staff are well placed to monitor and report residents' pain, and there are actions they, like hospital nurses, can take to improve the way they report pain. For example, they can:

- Keep a record of pain levels (a pain chart) that can be used to assess the effectiveness of pain control (see p. 14 of the workbook (*Pain chart*))
- If appropriate, ask residents to contribute to the record by answering a series of questions (see p. 15 of the workbook (*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?
- Support these questions with observations. For example, it will be obvious if a resident finds movement painful

Ask the group to think about ways in which the pain chart and the list of questions could be introduced into the care home, and the best place to keep them. Remember that both staff and residents will need to use them.

## Session 2.4

10 minutes

### Discussion: resistance to prescribing strong painkillers

Facilitator text 2.2 (*Fears about prescribing opioids*) and further reading 1 (*Withdrawing versus withholding treatment*) provide useful background information for this session.

Ask participants for their comments on p. 9–10 of the workbook (*Fears about prescribing opioids*), which they were asked to read at the end of workshop 1.

#### Discussion points

Raise the following points if the group does not.

#### *Morphine myths*

Many care-home staff have seen morphine (one of the opioid drugs) administered to dying residents in pain, and may wrongly believe that the drug hastens death or that its use is a form of euthanasia. This belief may be strengthened when they see that some doctors are unwilling to prescribe morphine. This attitude might be difficult to change, especially when it seems

to be supported by experience. Page 9–10 of the workbook (*Fears about prescribing opioids*) addresses the common objections to the administration of morphine. Emphasise and expand the facts about the drug, if necessary. It might be helpful to illustrate the point with this example from palliative care: some patients receive opioid treatment for several years at a relatively high dose and yet remain alert and able to manage their daily routines.

#### *Pain can shorten life*

There is a lot of evidence to suggest that pain is more likely to shorten a person's life than pain-relief (analgesic) medication; when pain and symptoms are relieved, people often live longer than predicted.

#### *Whose right to choose?*

Raise the issue of whose right it is to choose whether or not a person should be in pain when pain relief is available. Is it possible for anyone other than the person in pain to know what is in his or her best interests?

#### *Ethical treatment*

Offering adequate and effective pain and symptom relief to all residents when they need it, rather than just in the last few days or weeks of life, is the only ethical way to help them.

### **General information: the analgesic ladder**

Direct participants to p. 16 of the workbook (*The analgesic ladder*).

#### **Teaching points**

The following points are based on facilitator text 2.3 (*Using drugs for the treatment of pain (analgesia)*). The analgesic ladder will be new to most, if not all, of the group. Explain that it is not necessary to remember the detail but it is helpful to understand the approach, and that it has been adopted in palliative care as the most effective approach to treating pain. You may also need to explain that analgesic drugs are painkillers, and that there are several different types of analgesic drugs (including opioids such as morphine) with different strengths.

#### **The analgesic ladder**

The WHO recommends that pain should be treated with three types of drugs – non-opioids (step 1), weak opioids (step 2), and strong opioids (step 3), which can all be used at the same time. In other words, a resident taking step-1 drugs who requires added pain relief can be given step-2 drugs in addition to those he or she is already taking. For patients in severe pain, it may be necessary to give drugs from all three categories. Also, step-3 drugs can be prescribed at the start of treatment for people in severe pain, without working through step-1 and step-2 drugs first.

## **Session 2.5**

15 minutes

- Step 1: non-opioid drugs for mild pain, such as paracetamol (sometimes called Panadol) (two 500-mg tablets every 4–6 hours, up to a maximum of 12 tablets/day)
- Step 2: weak opioids or a combination of a non-opioid and a weak opioid drug for moderate pain, such as paracetamol and codeine, tramadol, or dihydrocodeine
- Step 3: strong opioids for moderate and severe pain, such as morphine, diamorphine, and fentanyl. Morphine is available in two formulations – fast-acting liquid or tablets taken by mouth, often 4-hourly, and slow-release tablets or granules taken every 12 or 24 hours. Diamorphine is given by injection or by syringe driver. Fentanyl is administered via skin patches that are changed every 3 days. The number of patches can be increased as and when necessary.

The principles for prescribing opioids are:

- Opioids should be given regularly
- Extra doses should be given for extra pain
- Opioids should be prescribed in adequate dosages (range 2.5–2500mg, 4-hourly)
- The maximum dosage is that beyond which no extra pain relief is provided, or side-effects become unacceptable
- The correct dose is worked out on the basis of the patient's size, frailty, and previous pain-relief needs
- Opioids should be given by the most appropriate route. For example, a syringe driver should be used to administer opioids continuously in patients who need regular injections. This avoids frequent painful injections and provides a way of preventing pain rather than treating it when it occurs
- Drugs to relieve other symptoms can be mixed in the syringe with the opioid and given at the same time. NOT ALL DRUGS CAN BE ADMINISTERED IN THIS WAY

## Session 2.6

15 minutes

### Discussion: causes and treatment of other symptoms

Explain that you would now like to spend some time on symptoms other than pain.

Ask participants to suggest the common symptoms that residents experience, the causes, if known, and how the symptoms are treated. Ask them to focus on residents with chronic conditions who are not necessarily thought to be dying. Summarise the responses on the flipchart.

#### Discussion points

You might find it helpful to group the symptoms mentioned by body system, as shown below. Also, encourage participants to make connections between symptoms and causes.

*Heart and circulation*

Symptoms include those caused by angina and heart failure, such as acute angina pain, breathlessness, reduced mobility, swelling due to fluid retention (oedema), poor circulation in the hands and feet that leads to reduced use of these limbs, leg ulcers, and gangrene.

*Respiratory system*

Symptoms include those caused by chest infections (such as bronchitis), chronic obstructive airways disease, emphysema, and lung cancer, such as cough, breathlessness, high temperature, and loss of sleep.

*Bones, joints, muscles, and skin*

Symptoms that affect the bones and joints include those caused by arthritis and fractured bones that reduce mobility and cause joint pain and chronic backache. The skin can become very dry and itchy in residents who stay in one position for long periods of time. Such residents are also at risk of pressure sores, and the risk is increased in residents who are over- or under-weight or who are incontinent.

*Digestive system*

Digestive system symptoms include indigestion, heartburn, nausea, vomiting, stomach pains and cramps, lack of appetite, constipation, diarrhoea, weight loss, sore mouth, difficulty in swallowing, flatulence, drug side-effects (gastric upset, constipation), and the general and long-term effects of poor nutrition and dehydration.

*Nervous system*

Damage to the nervous system might cause confusion, disorientation, headaches, loss of hearing, loss of sight, incontinence, dizziness, drowsiness, insomnia, and reduced mobility.

*Secondary effects*

These symptoms can also have secondary effects. For example:

- A person who does not eat well might become confused as a result of a vitamin deficiency
- A person whose movement is reduced and who cuts down fluid intake to avoid going to the toilet can become constipated and dehydrated which, in turn, leads to confusion and other symptoms
- Residents who are no longer able to read might become depressed
- Residents whose hearing is impaired might feel isolated and unwanted

**Teaching points**

The following points are based on facilitator text 2.4 (*Principles of symptom control*). Space is provided on p. 17 of the workbook if participants wish to

make notes.

As with the recognition of pain, the recognition of other symptoms and their causes is crucial to symptom control. The basic principles of symptom control are:

1. Diagnose the cause of the symptom
2. Explain the significance and implications of the symptom to the resident
3. Discuss treatment options
4. Set objectives that are realistic
5. Anticipate
6. Ensure that relatives remain informed and supported
7. Treat appropriately
8. Review the treatment plan frequently
9. Never say 'There is nothing more I can do'

## Session 2.7

25 minutes

### Discussion: management of the common symptoms associated with ageing

This session is based on facilitator text 2.5 (*Management of general symptoms*).

Ask participants to talk about the techniques used in the care home to manage pain and other symptoms. Ask them to relate specific examples they have noted down in their journals. You may also need to refer to the notes made in session 1.4 and 1.6.

#### Discussion points

Focus the discussion on the specific actions care-home staff can take to help residents. Participants will probably concentrate on drug treatments, but encourage them to consider the other techniques and skills they use to control pain and other symptoms, such as:

- Staying with a resident who is afraid of being alone
- Listening to residents who are depressed (see module 2)
- Simple techniques to relieve pain, such as the application of heat or a change in position

It might be useful to summarise the actions care-home staff can take and the areas in which they might need to ask for specialist help. Some of the discussion will be about problems beyond the ability of care-home staff to resolve. Part of the skill of palliative care is recognising when to ask for specialist help and support.

#### Teaching points



Use your notes on facilitator text 2.5 (*Management of general symptoms*) as the basis for teaching points, and briefly cover each section in the text. Since the text is useful reference material, it is reproduced on p. 18–22 of the workbook. You might like to make some photocopies to be made available to all the care-home staff (including new members of staff).

### Closing remarks

## Session 2.8

5 minutes

- Thank everyone for taking part in this intensive workshop
- Point out that the workshops will help them build on their life skills and experience
- Suggest that participants record their thoughts about the workshop in their workbooks on p. 23 and how it might affect their practice. Also suggest that they record any thoughts and observations with respect to the management of residents' pain and other symptoms, and remind them to bring their workbooks to the next workshop
- Agree the date, time, and place of workshop 3, and ask participants to write the information in the box provided on p. 23 of their workbooks. Remind them that it will address some of the practical aspects of addressing residents' need for pain and symptom control

## Facilitator text 2.1

# Pain and symptom management

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.<sup>1</sup>

## Introduction

Despite the availability of effective methods to relieve pain, there is evidence to show that healthcare professionals manage pain poorly. As a result, patients suffer pain unnecessarily.

In the care-home setting there is an ethical and a professional duty to prevent residents from suffering pain needlessly and to relieve it to an extent agreed with the residents in pain. The use of systematic assessment and documentation contribute to effective pain management, as do efforts to understand the experience of pain. The following text provides guidance on how better to understand the experience of pain and on the reporting and assessment of pain.

## Pain must be understood

Since it is impossible to know exactly how another person experiences pain, it is difficult to understand it. However, there are a variety of words that can be used to describe residents' pain in written reports. The following groups of words are taken from a questionnaire used to assess pain (the McGill Pain Questionnaire):<sup>2,3</sup>

1. Flickering, quivering, pulsing, throbbing, beating, pounding
2. Jumping, flashing, shooting
3. Pricking, boring, stabbing, drilling
4. Pinching, pressing, gnawing, cramping, crushing
5. Tugging, pulling, wrenching
6. Tingly, itchy, smarting, stinging
7. Dull, sore, aching, hurting, heavy
8. Tender, rasping, splitting, taut

Words that are commonly used to describe the effect of pain are:<sup>2,3</sup>

1. Tiring, exhausting
2. Sickening, suffocating
3. Frightful, terrifying
4. Punishing, gruelling, cruel, vicious, killing
5. Wretched, binding

6. Annoying, troublesome, miserable, intense, unbearable
7. Agonising, dreadful

The following words describe the intensity of pain:<sup>2,3</sup>

1. Mild
2. Discomforting
3. Distressing
4. Horrible
5. Excruciating

Finally, pain might also be:<sup>1,2</sup>

1. Constant
2. Rhythmic
3. Intermittent

### Pain must be assessed and documented

Pain assessment is central to pain management and is a key role of care-home staff. A pain assessment tool is useful, such as that shown on p. 14 of the *Participant's workbook (Pain chart)* in which a number of words have been brought together to describe not only pain intensity but also the experience of being in pain. Such tools also provide an accurate measure of changes in residents' experience of pain and the effectiveness of pain-relief techniques or medication.

The systematic recording of the levels of pain experienced by a resident on a pain chart provides a means of increasing the awareness of the pain, and of monitoring the need for pain relief and its effectiveness. It is also a means by which all carers can be informed about the condition of the resident, provided that, like a temperature or a blood pressure chart, it is easily accessible.

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### References

1. The Open University. *Palliative care handbook*, course K260. Milton Keynes: The Open University, 2000;7–17
2. Melzack R. The McGill Pain Questionnaire: major properties and scoring methods. *Pain* 1975;1:277–99.
3. Davey B, Seale C. *Experiencing and explaining disease*. Buckingham: The Open University, 2002.

## Facilitator text 2.2 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.<sup>1</sup>

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 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 illness. The major fears are:

### 1. Addiction

#### **Patients will become addicted to opioids.**

Fear of addiction is a concern among many professionals and patients. There is no evidence that this belief is true. On the contrary, there is much evidence that opioids, when given in the right way for an appropriate indication, are not addictive. It is important to distinguish between addiction and physical dependence. Addiction is a compulsion or over-powering drive to take the drug in order to experience its psychological effects. Physical dependence means that, if the drug is suddenly withdrawn, the patient will experience unpleasant physical effects; hence the drug, when being stopped, has to be withdrawn gradually.

If a patient is taking regular opioids for chronic pain, psychological addiction does not occur. Some patients on an 'as required' regime may appear to be addicted. This is because on such a regime their pain will be poorly controlled and they may ask for more opioid than they need because of fear of the pain getting out of control. They lose all their addictive behaviour as soon as they are treated in the right way – by an effective dose at regular intervals. Equally, patients whose pain is treated by another method, for example surgery or radiotherapy, do not display drug-seeking behaviour. If they are pain-free they happily stop the opioids. In a large survey of about 12,000 patients by the Boston Collaborative Drug Surveillance Program only four patients were considered to be addicted and only one had signs of major dependence.

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 titrated downwards.

## 2. Tolerance

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

Tolerance means that successive increases of dose are needed to achieve the same effect in chronic treatment. Most tolerance problems are associated with 'as required' administration which provides maximal side-effects together with minimal analgesic effects. When morphine is used for chronic cancer pain, tolerance does not occur. Most patients can be treated effectively by a stable dose of opioid and have been on morphine for long periods of time (years), and there is no evidence, even in these situations, that they become significantly tolerant to oral morphine. If the dose of opioid needs increasing, then the reason for this is that the underlying cause for the pain has progressed. 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 morphine in frail patients or those with respiratory problems as it precipitates respiratory depression. If patients are given a high dose of opioid then one of the side-effects is that their breathing deteriorates.**

A pain-free volunteer would develop respiratory depression when given morphine at moderate doses. By contrast, a patient with cancer pain will tolerate an enormous dose of morphine without any effect on respiratory effort. The only difference between these two situations is the pain, which seems to be a potent respiratory stimulant. When opioids are used correctly and the dose is gradually titrated upwards, respiratory depression is not a problem.

In fact, 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.

## 4. Signals imminent death

**The doctor has given me morphine. I must be close to death.**

The tendency for many professionals to prescribe morphine late in the patient's illness reinforces lay people's perceptions that morphine is used only in extreme circumstances. Therefore, when it is suggested that the patient be given morphine, they fear the worst. The prescription of morphine is thought to be an unspoken signal that death is imminent. Good communication and simple explanation that this is not the case at the time of the prescription could allay this unfounded fear.

## 5. Hastening death

**I cannot prescribe morphine until the patient is close to death; I like to reserve morphine until the very end.**

As has been stressed before, this attitude leads to poor analgesic control and distress for the patient. Opioids do not hasten death; in fact they improve the quality of living. It is quite often the case that when patients have their pain relieved by morphine they are able to mobilise pain free, eat again, and enjoy their life.

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### Reference

1. The Open University. *Palliative care handbook*, course K260. Milton Keynes: The Open University, 2000;21–2.

## Facilitator text 2.3

## Using drugs for the treatment of pain (analgesia)

In the treatment of pain a wide variety of analgesic preparations are available. However, prescribing should be limited to a relatively small number of drugs. It is in the best interests of the patient and doctor to use a few drugs well rather than a large number of drugs badly. The following text, which is an extract from the *Palliative care handbook*, summarises WHO recommendations.<sup>1</sup> The extract is reproduced by permission of The Open University.

### Analgesic ladder

In 1996, the WHO advocated that pain should be treated by the use of three types of drugs, as follows (see figure):

#### WHO analgesic ladder.<sup>2</sup>

##### Step 1 Mild pain

##### Non-opioids

e.g. paracetamol  
Two tablets every 4–6 hours

##### Step 2 Moderate pain

##### Non-opioids/weak opioids

Mixture or weak opioids

e.g. codeine, dihydrocodeine with paracetamol, tramadol (pain caused by nerve damage)

##### Step 3 Moderate/severe pain

##### Strong opioids

e.g. morphine, diamorphine  
Orally: must be given regularly  
Injection: not 'as required'

#### Step 1 Mild pain – non-opioids

A simple non-opioid painkiller such as paracetamol, two tablets taken every 4–6 hours, is often sufficient for mild pain. Paracetamol is preferred to aspirin because it does not cause inflammation of the stomach. If the pain is not relieved, then other simple painkillers are unlikely to suffice and one should move on to step 2.

#### Step 2 Moderate pain – weak opioids or non-opioid/weak opioid combinations

Dihydrocodeine alone or paracetamol/codeine, paracetamol/dextropropoxyphine mixtures are commonly used. Tramadol is a relatively

new opioid for both step-2 use and the lower end of step 3. It can be regarded as double-strength codeine. It may prove particularly useful in pain due to nerve damage.

### **Step 3 Moderate/severe pain – strong opioids such as morphine or diamorphine**

Morphine is the strong opioid of choice. Morphine is available in three forms that can be taken by mouth. The quick-acting preparations are taken every 4 hours (available as a liquid or tablets). The slow-release preparations are taken every 12 hours (available as tablets or soluble granules) or every 24 hours (available as tablets). Diamorphine hydrochloride is used if injections are needed.

Fentanyl is another commonly used step-3 opioid. It is given transdermally on a plaster that is changed once every 3 days and is absorbed through the skin. It is useful if patients have a problem taking drugs by mouth and as an alternative strong opioid to morphine if the side-effects of morphine prove problematic (see below).

## **Principles of opioid prescribing**

Opioids are safe, effective, reliable analgesics. Morphine and diamorphine are the strong opioids of choice and will control pain in the majority of people. The principles of prescribing opioids in people with advanced disease are simple and as follows.

### **Opioids should be prescribed regularly**

This is to suppress the pain and prevent it from breaking through between doses. To achieve this, quick-acting (4-hourly) morphine is usually used (tablet or liquid). In this form there is a rapid onset of painkilling action usually peaking within the first hour after taking the dose. Pain relief lasts for about 4 hours. This means the drug must be given every 4 hours, that is, six doses in a day.

### **'Rescue doses' of opioids should be available for any extra pain**

It is very important that any patient on a regime of regular opioids should have access to further analgesics that can be taken for any extra pain. They may be needed for pain that breaks through the regular dose (to be taken as and when the pain arises) or for pain which occurs with movement, weight-bearing, dressing change, or some other incident, when they should be taken 30 minutes before the anticipated incident. Pain control should be assessed at least every 24 hours initially. Where extra doses have been taken for pain that breaks through, the regular dose should be adjusted accordingly.



**Opioids should be prescribed in adequate doses**

The dose of the opioid should be tailored to each patient. There is no upper limit on dose. Having started the patient on the opioid, the dose is steadily increased until maximum pain control is achieved. The maximum dose is the dose beyond which the patient either gains no extra pain-relieving effect or beyond which they experience unacceptable side-effects. There is a remarkably large dose range, which varies from about 2.5mg 4-hourly to 2500mg 4-hourly, or more. The majority of patients are on 60mg 4-hourly, or less. Many factors contribute to the variation in dose between individuals or in the same individual at different times. The absorption of the drug, the severity of the pain, the type of pain, and any psychosocial component are major factors.

**Opioids should be given by an appropriate route**

Ideally opioids should be given by mouth. This is simpler for patients and allows them to retain control to a large extent. However, at times this may not be possible and the drugs may need to be given either by the transdermal route, rectal route, or by injection. Reasons why patients are unable to take oral morphine include:

- Vomiting
- Nausea
- Bowel obstruction
- Severe weakness, making it impossible for the patient to swallow in a coordinated way
- Unconsciousness
- Inability to tolerate a large number of tablets or the taste of the liquid form

Most patients who cannot take morphine orally prefer injections to suppositories.

If a patient needs regular injections of morphine, then a syringe driver delivering a continuous subcutaneous infusion should be used, otherwise the patient is subjected to six injections every day. Also, the delivery is continuous and avoids the possibility of pain building up. The syringe driver is a small battery-driven device that will inject the contents of a syringe over a 24-hour period under the skin. It can be used at home as well as in the inpatient setting. When in use it should not significantly hinder the mobility of the patient. The syringe is placed in the battery-driven pump and a long piece of fine tubing connects it to a needle that is placed under the skin of the upper chest, upper arm, or the abdomen.

One of the great advantages of the syringe driver is that, in addition to delivering analgesia subcutaneously, other drugs can be mixed with the diamorphine so that the patient can receive anti-emetics, sedatives, and drying agents via the syringe driver.

## References

1. The Open University. *Palliative care handbook*, course K260. Milton Keynes: The Open University, 2000;18–20.
2. World Health Organisation. *Cancer pain relief*. Geneva: WHO, 1996;33.

## Principles of symptom management

This text includes extracts taken from The Open University *Death and Dying* course (K260), workbook 2, *Caring for Dying People*, which are reproduced by permission of The Open University.<sup>1</sup>

### Common symptoms

Pain is said to be one of the most common symptoms and is feared by many people but dying residents suffer from many other symptoms. Probably the most common symptom is the feeling of weakness, debility, and malaise which goes with having an advanced disease. Yet this symptom is perhaps the most difficult to treat. But, even just to have the symptom acknowledged and explained can go a long way towards helping the resident cope with it.

For symptom management to be successful, the dying person needs to be central to the whole process of exploring the symptoms with the carers, both informal and professional. Initially it is advisable to attempt to separate symptoms out.

### Basic principles

The basic principles of symptom control are:

1. Accurately diagnose the cause of the symptom
2. Explain the significance and implications of the symptom to the dying resident and carers
3. Discuss treatment options
4. Set objectives that are realistic
5. Anticipate
6. Ensure that relatives remain informed and supported
7. Treat appropriately
8. Review treatment plans frequently
9. Never say 'There is nothing more I can do'

#### **1. Accurately diagnose the cause of the symptom**

It is vital to know the cause of each symptom so that suitable treatment can be initiated. Both the physical and psychological elements must be taken into account.

It cannot be emphasised too strongly that careful history and examination alone will elicit the cause in most instances. If the diagnosis is dependent upon investigations that are difficult and distressing then the benefits

accruing from the investigation must be weighed against the discomfort caused.

The importance of knowing the cause of a symptom becomes clear when one realises that the treatment of the same symptom may well vary considerably depending on the underlying pathological process.

When a diagnosis has been made, appropriate treatment should be instituted. However, there are situations in which it is impossible to be sure of the exact cause and therefore a tentative diagnosis has to be made.

## **2. Explain the symptom to the resident**

The fact that the symptom is understood and acknowledged as a problem can in itself be therapeutic by allaying to some extent the resident's fears. The resident will appreciate that if the symptom is understood then there is a real chance that effective treatment can be offered. This will help to overcome natural fears and anxieties which can actually exacerbate symptoms and alter the resident's interpretation of them.

## **3. Discuss treatment options**

All residents need to be given adequate and accurate information in order to make an informed choice between management options. By giving this, you increase the individual's sense of control and allow them to feel they can participate in the decisions being made about their future.

## **4. Set objectives that are realistic**

If a resident in pain is told that they will be prescribed a tablet which will get rid of all their pain, but this does not happen, the resident then loses trust in the professional carers. This leads to doubts about the carers' ability to control any symptoms and hence to anxiety on the resident's part that they will have to suffer uncontrolled symptoms. If staff have unrealistic expectations, either of the efficacy of their treatments or of the resident's abilities, then when these expectations are not fulfilled, the staff become frustrated and will have difficulty in motivating themselves. Despite the advanced nature of the illness, there are achievable goals.

## **5. Anticipate**

People with advanced disease often have rapidly changing symptoms, many of which can be anticipated. Strategies can be developed which will minimise potential distress. For instance, as the resident's general condition deteriorates, there may well come a time when they are unable to swallow tablets or liquids. When this happens there are certain medicines which must be continued for the patient's comfort – painkillers, anti-sickness medication, and so on. These drugs will now have to be given either in the form of suppositories or injections and supplies of the appropriate form of the medicine left in the home. It can often take several hours to get hold of a

suitable drug from local chemists and therefore anticipatory prescribing is essential.

## 6. Ensure relatives and patients are well informed and supported

It is always important to recognise that care must be delivered to both the resident and 'any family'. A well-supported family will cope much more effectively with the stresses inherent in caring for their loved one.

## 7. Treat appropriately

Prescribing should be simple. Doctors should always prescribe:

- Rationally and give the
- Right drug at the
- Right dose. Use the
- Right interval and give by the
- Right route. Prescribe
- Regularly and explain the
- Regime to the patient

The *right drug* must be chosen. For example, although many pains respond to morphine-like painkillers, not all do. Morphine is not therefore the right drug for all pains and in certain instances other drugs or therapies are indicated. Again, in prescribing the right drug, one may be put in a position where it is necessary to prescribe a further drug to counteract some of the unwanted effects of the former while retaining its beneficial effects. For example, many painkillers cause constipation and therefore a laxative has to be given at the same time.

The drug must be given at the *right dose* – failure of therapy may be due to the fact that simply not enough of a drug has been prescribed, or alternatively it may be that too high a dose is given and causes unnecessary and unacceptable side-effects leading the patient to abandon the therapy.

The *right interval* between doses is also crucial. For example, the slow-release version of morphine should be taken every 12 hours whereas the ordinary form has to be taken every 4 hours in order to be effective. This is because each type is absorbed and excreted by the body differently and this influences how long its effect will last.

The *right route* has to be chosen – there is little sense in giving drugs by mouth if the resident is vomiting. In such circumstances the drug will have to be given either transdermally, rectally as suppositories, or by injection.

## 8. Review treatment plans frequently

This is essential as a dying person's condition can change rapidly.

### 9. Never say 'There is nothing more I can do'

This statement is negative, unhelpful, and not true.

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### Reference

1. The Open University. *Palliative care handbook*, course K260. Milton Keynes: The Open University, 2000;9–12.

## Management of general symptoms

This text includes extracts taken from The Open University *Death and Dying* course (K260), workbook 2, *Caring for Dying People*, which are reproduced by permission of The Open University.<sup>1</sup> 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 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.<sup>2</sup>

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.<sup>3</sup>

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

### Dyspnoea (breathlessness)<sup>1</sup>

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.<sup>4</sup> 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

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## References

1. The Open University. *Caring for Dying People*. Workbook 2, course K260. Milton Keynes: The Open University, 2000;42–45.
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

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

## Facilitator preparation

Before the workshop you will need to:

- Remind participants of the date, time, and place of the workshop, and ask them to bring their workbooks and a pen
- Study the facilitator guidelines and the following further reading:
  - Further reading 2 (*Ending life-prolonging treatment*), which provides a discussion of the ethics of stopping life-sustaining treatment
  - Further reading 3 (*Management of the terminal phase of the illness*), which provides guidance on what to expect in the last days and hours of a person's life, and care management during this time
- Remind yourself of the main summary points of facilitator text 1.2 of module 1 (*The case for palliative care in residential and nursing homes*)
- If necessary, make notes for the activities on the flipchart – keep them simple and clear
- Bring the agreed ground rules
- Prepare a celebration for the end of the workshop and for the signing of the certificates of attendance

# Facilitator guidelines

## Session 3.1

### Introduction

5 minutes

Welcome participants. Direct them to p. 24 of the workbook and explain the aim of this workshop, which is to understand strategies for the management of pain and other symptoms, and how to liaise effectively with other support workers.

Display the agreed ground rules.

Direct participants again to p. 24 of the workbook and run through the programme and timetable for workshop 3. Reiterate that as in other workshops, this one will require participants to take part in group activities and role plays.

## Session 3.2

### Small-group activity: a palliative-care approach

25 minutes

Divide the participants into three groups for some care-planning activities. If there are fewer than nine people, divide them into pairs, or just use two case studies. The cases of three residents are described on p. 25–26 of the workbook (*Three case studies*). Ask each group to plan the care for one of the residents described. Ask them to use the space provided to note down:

- The actions they would take
- The areas in which they would need more specialised help and support

Ask one member of each group to record the key points for the group.

## Session 3.3

### Feedback

10 minutes

Ask each spokesperson to report back to the whole group in turn. Before they do so, ask the group to read all the case studies.

#### Feedback points

Bring up the following points if the groups do not.

*Sally*

Staff might want to talk and listen to Sally and help her explore her feelings; they should not assume that they know how she is feeling.

There might be ways in which Sally could mark past deaths that have been a source of loss and pain. For example, she might be able to talk through her feelings or she might be able to create a memorial of some kind, such as by planting flowers in the garden.

Staff might also consider whether Sally has any friends in the home with whom she could spend more time? She has lived there for 12 years and is likely to have many friends among both the residents and staff. A priority

would be to provide Sally with some company, if that is what she wants. However, she may prefer to be left alone. You might encourage the group to debate the extent to which it is ethical to intervene in this type of choice. (Note: further reading 2 (*Ending life-prolonging treatment*) might help in this discussion).

Staff might consider referring Sally for psychiatric assessment if they think she is very depressed.

### *Harold*

Harold is clearly in need of specialist help for his muscle spasms. He is going to deteriorate very rapidly without a lot of support, which might be provided by a specialist stroke nurse or a community physiotherapist, or both. One of the dangers of discharging people from hospital to care homes following a stroke is the assumption that home staff will be able to provide specialised physiotherapy.

Once Harold's problems caused by the stroke are eased, the care-home staff can begin to think about relieving his other symptoms. He will need a rehabilitation programme, help with walking (walking aids), treatment for his swollen feet and ankles, and good skin care.

Suffering a stroke and losing his home are both devastating events and Harold needs time and space to come to terms with them. He will need a lot of psychological support during his recovery.

### *Poppy*

Poppy is a good example of someone whose pain has become unmanageable and whose physical suffering, to her, is worse than living. Staff should obtain expert help to manage her pain, but should involve her in any decisions to be made.

Poppy's loss of appetite following flu is typical of the events in chronic degeneration that suggest a significant change in her condition. However, without eating, Poppy will feel increasingly worse. If her pain can be controlled her interest in food might be stimulated and the downward cycle arrested. Even though her remaining life might be short, Poppy should not have to experience pain and symptoms that can be relieved.

Discuss the difficulty that some care-home staff have in managing residents who seem to be very demanding; they might avoid or ignore them. Would they leave Poppy alone in her room to avoid upsetting other residents? This question might provoke a heated debate about residents labelled as 'difficult'.

## Session 3.4

15 minutes

### **Small-group activity: providing pain and symptom relief for dying residents (role play)**

Residents do not have to be dying to be in need of pain relief or relief from

other symptoms. Nonetheless, the following role-play activity focuses on the care residents receive when they are near death.

The role play can take place either in small groups or in one large group. Direct participants to p. 27 of the workbook (*Characters for role play*) and ask them each to choose a character to role play. Invite them to imagine that they have been called to a case conference to discuss the care needs of particular residents. Give them 2–3 minutes to prepare. They might start with Esther but go on to talk about residents in the home. The number of example cases you use will depend upon the size of the group and the time available.

Act as an observer and make notes for the feedback session, such as the elements of the discussion that were helpful, the amount of time spent discussing the needs of the resident, the amount of involvement of the resident and family in decisions, the need to evaluate any proposed treatment, and the effectiveness of the participants to communicate with each other.

## Session 3.5

### Feedback

10 minutes

The *Facilitator's manual* (p. 17–18) contains advice and how to provide constructive feedback on role play.

#### Feedback points

First, let participants give their own feedback on their role and their performance. Your comments should include:

- Your observations
- Relevant issues raised during the role play
- The information staff need to meet the resident's needs
- The skills staff need to negotiate care in this way
- The outcome participants wanted; were they clear about their objective
- Sources of support

#### Teaching points

Cover the following points, if they were not made during the feedback discussion.

Care homes are well equipped to provide particular types of care and support. For example, staff are more likely to be able to spend time listening to residents than if they worked in a busy hospital. Residents also benefit from being in familiar surroundings and from the staff's awareness of their individual needs. Staff can also get to know residents' family and friends and recognise the value of the resident's friends within the home.

Care-home staff often find the management of pain and other symptoms difficult; they are, for example, dependent on good GP and other community

support services to manage pain well. However, staff need to be aware of the support and advice that is available and how to ask for it. You might like to ask participants to find the contact telephone number for local palliative-care services and other support services (see p. 28 of the workbook). Local support services might include, in addition to healthcare services, bereavement counsellors and local priests and ministers of all relevant religions. The palliative-care approach depends upon teamwork and care-home staff are part of the team.

### Session 3.6

15 minutes

#### Discussion: improving the care of dying residents

A presumption that participants are committed to the principles of palliative care underpins this training programme (see module 1, workshop 1, facilitator text 1.2 (*The case for palliative care in residential and nursing homes*)). This session provides time for you to summarise the key points of this module and to discuss improvements in care. Address the following points in the discussion:

1. What can care-home staff do well?
2. What needs to be improved?
3. What could staff ask other professionals to do?
4. Are there support workers, such as the hospice home-care team, Macmillan nurses, and other palliative-care specialists, who might be able to help staff improve their care of dying residents?

If participants wish to make notes during this session, space is provided on p. 29 of the workbook.

#### Feedback points

After a general discussion, help the group develop a policy statement on pain and symptom control for the home, which they can write up on p. 30 of the workbook. This will help participants feel proud of what they do well, be aware of what they must improve, and commit to ask for additional specialist support when necessary. You might like to type up the policy statement and display it in the home, as well as give a copy to each member of staff (including new members of staff).

### Session 3.7

10 minutes

#### Closing remarks

- Thank everyone for taking part in the workshop and congratulate them on successfully completing module 3
- Point out that the workshops will help them build on their life skills and experience
- Suggest that participants record their thoughts about the workshop in their workbooks (p. 31) and how it might affect their practice, and that they keep their workbooks for future modules (if this is not the final module)



- Encourage participants to take part in the other modules. If they are already planning to do so, agree the date, time, and place of the next workshop, which will be the first of module 4 (*Bereavement care*) if you are running them in order. Otherwise, it will be the first workshop of module 2 (*Communication*). Ask participants to write the information in the box provided on p. 31 of their workbooks
- If this is the last module, thank everyone for taking part in the whole programme and ask them for their thoughts on how it will affect their practice
- Mark the end of the module by signing each participant's certificate of attendance, or invite the manager to do so

# Further reading

## Further reading 1

### Withdrawing versus withholding treatment

This text includes extracts taken from The Open University *Death and Dying* course (K260), workbook 3, *Dilemmas and Decisions at the End of Life*, which are reproduced by permission of The Open University.<sup>1</sup>

One of the problems for decision-taking about cessation of treatment is that some people feel that there's a moral difference between withdrawing and withholding treatment. Withdrawing a life-prolonging treatment might seem morally much worse to some people than deciding to withhold it – that is, not to start the treatment in the first place.

Why should we believe that withdrawing life-prolonging treatment once it's been started is morally worse than withholding it in the first place? Many people do have this belief but, in fact, it is quite hard to see what can justify it. The main reason seems to be that withholding treatment does not involve taking an action, whereas withdrawing treatment does. If we remove the tubes, or turn off the ventilator, we are doing something that can be thought of as bringing about a death. But if we decide not to insert the tubes in the first place, we are just omitting to do something, thereby allowing death to take place. So, in withholding treatment, some people feel, we are less morally responsible for the outcome than we are when we actually withdraw treatment.

But, this line of thought seems to rely on something like the acts/omissions doctrine – the view that acts are morally more important than omissions. If that doctrine were true, then it might give us reason to think that withdrawing treatment (i.e. acting) is morally worse than withholding it (i.e. omitting to act). But the acts/omissions doctrine is itself difficult to justify, so it cannot be of much help in explaining why withdrawing and withholding treatment might be morally different.

And, maintaining a moral distinction between withdrawing and withholding treatment can have very undesirable consequences. It can lead to under-treatment of patients, and paradoxically it can also lead to over-treatment of patients. If we initiate a treatment and then find that it is ineffective or has intolerable side-effects, we may be reluctant to withdraw it, on the grounds that although it would have been morally acceptable not to start it, it is morally wrong to withdraw it once started. In this case, we will be over-treating the patient, with the possibility of needless stress for him or her, and also the certainty of wasted resources in treating a patient who isn't being benefited by the treatment.

On the other hand, as long as we think that there is an important moral difference between withholding and withdrawing treatment, then we will be reluctant to start a treatment unless we are sure that it will benefit the patient. But with some medical procedures, we cannot really know whether it is right for a particular patient without trying it on her, to see how she responds. If we are reluctant to do that, because we feel it would be wrong to withdraw it once we had started, then we run the risk of under-treating the patient, of not giving her a treatment which might actually benefit her, because we are not sure in advance how beneficial it will be. But if we do not allow that there is a moral difference between withholding and withdrawing treatment, then we will not have this problem. We will be prepared to initiate treatments in the knowledge that if they are ineffective in some way, then we will not be morally obliged to continue with them. Recent British Medical Association guidelines endorse this view: 'Although emotionally it may be easier to withhold treatment than to withdraw that which has been started, there are no legal, or necessary morally relevant, differences between the two actions.'<sup>2</sup>

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## References

1. The Open University. *Dilemmas and Decisions at the End of Life*. Workbook 3, course K260. Milton Keynes: The Open University, 2000;104–6.
2. British Medical Association. *Withholding and withdrawing life-prolonging medical treatment*. London: BMJ Publishing Group, 1999.

## Further reading 2

# Ending life-prolonging treatment

This text includes extracts taken from The Open University *Death and Dying* course (K260), workbook 3, *Dilemmas and Decisions at the End of Life*, which are reproduced by permission of The Open University.<sup>1</sup>

When a patient nears the end of her life, there often are very difficult decisions about treatment and care which have to be taken. People feel strongly about many of these decisions, because they are matters of life and death, and we are anxious not to get them wrong. One such decision is about when to stop life-prolonging treatment. Is it ever appropriate to refrain from giving life-prolonging treatment? If so, when? And who should decide?

Consider the following two cases.

1. Pauline is elderly, and dying of cancer. She is in a lot of discomfort, and has now developed a chest infection. Even if she recovers from this, she is unlikely to have more than a very short period of increasing distress and disability before she dies. Should she be given antibiotics for the chest infection?

2. Roy is also elderly and terminally ill with cancer. He has a chest infection, for which he is already receiving antibiotics. He is very near death, and indeed some of the people looking after him are of the opinion that the antibiotics are really what is keeping him alive. Should his carers continue giving antibiotics to Roy?

In both of these cases, not giving the antibiotics involves not giving a life-prolonging treatment.

The first thing you might feel is that you need much more information before you could come to an informed decision. And, in real life this is of course correct – many other features of the situations, such as how certain the prognosis is, what the patients themselves want or would choose if they were in a position to make choices, and what the views of the relatives are about the patient's preferences, are all relevant to making the right decision here. But even the bare outlines of these two cases reveal three crucial questions that need to be answered about the possible cessation of treatment.

Firstly, what criteria should be used to make this decision? What is it about Pauline and Roy's situations that might make it right not to give them life-prolonging treatment?

Secondly, who should decide whether the criteria have been met? Should it be the patient? And if they cannot decide, should it be their relatives, or their health carers? And what about young children – who should decide for them?

Thirdly, is there any moral difference between ending treatment by withholding it, and ending treatment by withdrawing it? Pauline's case would involve withholding treatment, but Roy's case would involve withdrawing it. People who gave different answers to case 1 and case 2 will probably answer yes to this question. Many people do feel that deciding not to start a life-prolonging treatment for a patient may be morally justified in some circumstances, but if the treatment has already started, then it would be wrong to withdraw it, since that would be bringing about the patient's death. We need to ask, though, whether this widespread feeling can be justified and, in particular, whether withdrawing (or withholding) life-prolonging treatments amounts to passive euthanasia, as some people fear. We will look at these questions in turn.

### Criteria for not giving life-prolonging treatment

What criteria should we use for determining whether it is right not to give life-prolonging treatment? That is, what reasons could there be for thinking that life-prolonging treatment should not be given? Some people think there are no such reasons; life-prolonging treatments should always be given if available.

However, this view would mean that, for example, we would have to give cardiopulmonary resuscitation to every patient whose heart stopped (which

means everybody, sooner or later), and hence would be duty bound to put dying patients through very painful and distressing procedures if it gave them any extra lifetime at all, however poor the quality of that life. Because there seem to be moral problems of this kind about supporting provision of life-prolonging treatment on every occasion, many people are prepared to accept that in some situations there will be adequate reasons to refrain from treatment.

The most obvious reason for not giving life-saving treatment is that the patient has refused to accept it. Competent adult patients have a right to refuse any treatment they wish, even if all those caring for the person are convinced that the treatment would be in that patient's best interests, and even if without the treatment the patient will die. It does not, however, follow that competent adults also have the right to demand treatment.

Another major reason for not giving a life-prolonging treatment arises when the medical intervention would not be of overall benefit to the patient. If the benefit to a patient does not outweigh the burdens which the treatment would impose on him, then that would be a good reason for not giving the treatment. Here it must be noted that the concept of benefit which is being used is quite a wide one, according to which there are more benefits (and harms) than just the medical ones. So in trying to work out whether a given treatment would benefit the patient we need to go beyond the purely medical benefits. If, for example, a course of chemotherapy might prolong a patient's life by several months, then it may be regarded as being of medical benefit to the patient. But, if these months are going to be lived in a condition of severe pain and discomfort, or perhaps with limited consciousness and very little ability to interact with others, then it is not obvious that the treatment will actually be of overall benefit to the patient.

Some health carers are very reluctant to endorse decisions to refrain from giving life-prolonging treatment. They feel that deciding not to treat a patient, on the grounds that the treatment will not be of overall benefit to him, really amounts to giving up on a patient. They feel that it amounts to saying that the patient is worthless, or that his life is worthless. But is this really so? Are we bound to think that if the life-prolonging treatment is not a benefit to him, it follows that he is not himself of worth? In normal circumstances, of course, continued life is a benefit to patients, the greatest benefit that can be given them. But there are some situations in which this is not so, where continued life is burden rather than benefit, and we need to see how acknowledging this is not a way of saying that the patient is worthless, but rather a way of concentrating on what is actually in his best interests.

The British Medical Association guidelines draw an important distinction here that can help us see how cessation of treatment doesn't imply that the patient is worthless.<sup>2</sup> 'It must always be clear that the doctor's role is not to assess the value or worth of the patient, but that of the treatment. If the latter cannot benefit the patient, in terms of restoring that person's health to

a level that he or she would find acceptable, its use must be open to question.'

Normally, life-prolonging treatments are of very great benefit indeed to a patient. But where they are not, then not providing them does not amount to thinking of the patient as valueless, but rather to thinking of the treatment as valueless in this particular case, for this particular patient.

## Who decides?

Who is to decide whether a particular treatment is of overall benefit to a particular patient? If the criterion for giving or not giving a treatment is whether it will benefit the patient, who is to decide whether this standard has been met in a particular case?

The most obvious person to make this decision is the patient. She will normally have an understanding of her own interests, and of what will benefit her, that is better than anyone else's, and if she is competent she should be consulted about decisions to cease treatment. But what if the patient concerned is not competent to decide, or is unable to communicate her preferences? Who then has to decide whether the treatment should not be given? If the incompetent patient is an adult, then no other person, not even close relatives, can consent for her, though they may be able to provide valuable evidence about what the patient would have wanted had she been in a position to make and communicate her own choices. The healthcare team have to decide, on the basis of what is in the patient's best interests, whether or not to provide the treatment. If the patient, when she was competent to do so, made an advance directive covering the current situation, then the carers will be obliged to conform to it. Even if there is no advance directive, they should take into account any evidence there is of what the patient would have wanted, since that's some kind of evidence of whether this treatment would actually benefit her. This is the principal reason for consulting relatives; they cannot consent for the patient, but they may well have information about what the patient would have wanted. But where there is no such evidence, the decision has to be made on the basis of her best interests, and if the treatment would not benefit the patient, then we'll be justified in not providing it.

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## References

1. The Open University. *Dilemmas and Decisions at the End of Life*. Workbook 3, course K260. Milton Keynes: The Open University, 2000;100–1.
2. British Medical Association. *Withholding and withdrawing life-prolonging medical treatment*. London: BMJ Publishing Group, 1999.

## Further reading 3

## Management of the terminal phase of the illness

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.<sup>1</sup>

The terminal phase usually represents the last few days/hours of someone's life. When people enter the terminal phase, irreversible changes take place and death is inevitable. Symptoms should be evaluated and appropriate treatment instituted. As far as possible problems should be anticipated in order to avoid a crisis developing.

Good communication is essential. It is vital that explanation of the anticipated changes in the resident's condition be given to the carers and the resident (if possible). Relatives should be told about changing patterns of respiration. Changes in the pattern of respiration are normal in dying people. The breathing rate comes in waves of increasingly rapid respirations, and then the breathing may stop for a while. This leads to a fall in oxygen levels in the blood which stimulates the breathing to start again. The breathing starts slowly at first and then the rate gradually increases once again. This is known as Cheyne-Stokes respiration and is usually seen hours before death.

People become weak, there is no coordination of the muscles of the throat which makes swallowing difficult and secretions may build up at the back of the throat or in the lungs. The resultant noisy moist breathing is known colloquially as the 'death rattle'. It should be explained that this symptom can be controlled to a large extent with drugs, and probably causes the relatives more distress than the patient.

A degree of dehydration is inevitable in this phase and many practitioners believe that this is a normal part of the physiological process of dying. Good mouth care is usually all that is necessary to keep the patient comfortable. In some circumstances giving fluids may be necessary to control distressing symptoms (in people who complain of thirst, in agitated patients whose confusion is thought to be related to their dehydration).

When a patient becomes unconscious all drugs should be stopped apart from those aimed at symptom control and it is vital that such symptom control should be of the highest order. Clearly the wishes of the patient are important when these decisions are made. Analgesics should be continued even if the patient becomes unconscious. A physical withdrawal reaction may be precipitated if opioids are stopped abruptly. Patients who are already on regular opioids will need the equivalent dose subcutaneously (usually given as diamorphine). If more than two or three injections will be needed a continuous infusion is usually started.

## Agitation

Sedation may be needed but first any easily reversible cause should be treated. For example, urinary retention, which can cause severe agitation, will require catheterisation. Patients close to death may become agitated for no clear reason, a condition known as 'preterminal agitation'. In this context the agitation is irreversible. The aim of the team caring for the patient in the terminal phase is to allow the patient to have a peaceful death with their symptoms well controlled. It is their duty to the patient. A peaceful death will lead to far fewer bereavement problems for those that remain.

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## Reference

1. The Open University. *Palliative care handbook*, course K260. Milton Keynes: The Open University, 2000;44–5.







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](http://www.professionalresources.org.uk/macmillan)



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