For Unit EOL 302
Managing symptoms in end of life care

What are you finding out?
An early assessment of an individual’s needs and wishes as they approach the end of life is vital to establish their preferences and choices and identify any areas of unmet need. It is important to explore the physical, psychological, social, spiritual, cultural and, where appropriate, environmental needs and/or wishes of each individual.

Managing symptoms, including pain, is an important part of end of life care. Each person will have different symptoms depending on their condition and the kind of treatment they may be having. Good management of symptoms in the final phase is one of the main concerns of people and their families. The physical comfort of dying patients requires thorough assessment, clear communication and careful prescribing.

The reading and activities in this chapter will help you to:
- Understand the effects of symptoms in relation to the delivery of care
- Understand symptoms that identify the last few days of life may be approaching
- Understand the therapeutic options available to a person.
LO1 Understand the effects of symptoms in relation to end of life care

Identify a range of conditions where you might provide end of life care

Around 500,000 people die in England each year. The vast majority (around 99 per cent) of deaths occur in adults over the age of 18 years, and most occur in people over 65 years. The majority of deaths occur following a period of chronic illness related to conditions such as heart disease, liver disease, renal disease, diabetes, cancer, stroke, chronic respiratory disease, neurological diseases and dementia (http://www.endoflifecareforadults.nhs.uk/assets/downloads/pubs_EoLC_Strategy_1.pdf).

‘End of life care’ is for anyone with an advanced progressive illness, for example, people living with cancer or cardiovascular disease, neurological conditions and many more.

This care includes the management of pain and other symptoms at the end of life, as well as psychological, social and spiritual support to help achieve the best quality end of life care for patients and their families.

Health professionals are cautious about saying when they think someone will die. Over time, they should have a clearer idea of how long the person has to live, although they can never be exact. Indicators that they will look to include:

- The impact that symptoms are having on a person’s well-being
- Increasing weakness of muscles and dependency on others
- Loss of appetite and inability to swallow tablets
- Levels of consciousness.

The age profile of people at the time of death and the relative frequency of different causes of death has changed radically since the start of the past century, when infectious diseases were the major killers in this country.

Time to reflect

1. Conditions requiring care at end of life

Do you know much about the conditions discussed? Are there others you know about?

Changes occur as a person’s illness progresses because of the impact of the illness on the body’s ability to function normally. Doctors and nurses monitor the person’s physical condition and symptoms to see how they are affecting the person’s wellbeing.

It is very hard to predict how long a person has to live and exactly when they will die because life expectancies vary from one person to the next. It also depends on the type of illness and the person’s response to it.

Evidence activity

1.1 Signs and symptoms of liver disease

A person has been admitted to your setting with liver disease. What signs and symptoms might be present?

1.2 Identify common symptoms associated with end of life care

It is now recognised that a person has needs beyond their physical care; therefore it is important that the whole care needs of the person are met. Care should be planned to take into consideration the religious, spiritual, psychological, social and cultural as well as physical needs. This means looking at an individual as a whole person, rather than just focusing on their medical condition.

Time to reflect

1.2 Discussing your personal wishes and preferences

How would you feel about discussing your personal wishes and preferences?
It is important that you are aware of the services that are available and that you know when these services should be accessed. The appropriate professional will assess the person’s needs, and ensure appropriate care is put in place. The team will take a holistic approach to care, which means they will take into account all aspects of the service user’s well-being, including their:

- physical symptoms – e.g. pain, nausea, vomiting, difficulties with eating and drinking, constipation and breathlessness
- psychological symptoms – e.g. anxiety or fear
- spiritual issues – e.g. examining feelings and considering questions such as ‘Why is this happening to me?’ and ‘What will happen after I die?’
- social issues – e.g. looking at the best place to support the person, whether this be at home or in a care home, and also considering practical issues such as deciding where the person wishes to die.

Within your healthcare environment there should be members of staff with experience and training in looking after people who are nearing end of life, and can advise other members of staff in the support of these people. In nursing homes, there should be nursing staff with appropriate skills in palliative and end of life care. All care staff should receive some training in looking after people who are dying and be aware of their physical, spiritual and emotional needs, in order to facilitate a holistic approach to care. It is vital that care staff should also only act within their level of competence, and should know when and how to call upon other members of the team for support.

### Evidence activity

**1.2 Jemima**

Jemima has just been admitted to your setting. Draw up a plan detailing the approaches you will use to find out about her holistic needs and identify the areas you will ask about.

**1.3 Explain how symptoms can cause an individual distress and discomfort**

Types of pain that constitute total pain include:

- **Physical pain** – this can be caused by disease, injury or psychological stress factors. Severity will vary.
- **Emotional or psychological pain** – fear is the emotional pain most people associate with the stress of facing one’s own death. However, the issues faced can also lead to depression, anxiety or guilt.
- **Social pain** – news that an individual is dying may have a great impact socially. Isolation and loneliness may result as the person’s condition deteriorates and they lose social contacts.
- **Spiritual pain** – people may lose hope and not be able to make sense of what is happening. They may have difficulty finding a purpose to life. These factors may cause great pain.
- **Religious pain** – a dying person may feel as if they have been deserted by God or are being punished. Lack of access to places of worship and ministers of religion and being unable to carry out religious rituals may also increase pain.
- **Cultural pain** – people may feel cut off from their culture and community or country. They may experience a language barrier, which means they cannot always make their needs and wishes known. Some individuals may become distressed by others’ lack of understanding and respect for cultural issues such as ritual, customs, traditions or dietary requirements.
All types of pain should be viewed as a whole. Treating physical pain is obviously a priority, as this may in itself cause emotional pain. However, it must also be recognised that other types of pain can increase or aggravate physical pain – therefore, treatment for other types of pain can contribute to the relief of physical pain.

Evidence activity

Finding out about complementary therapies

A person says they do not know anything about complementary therapies. How can you help them find out more about them?

Evaluate the significance of the individual’s own perception of their symptoms

The strong emotions experienced by people receiving personal care

Individuals who have a life-limiting illness and who are unable to independently meet their personal care needs will have these needs met as part of the palliative care package. An individual not only has to come to terms with their life-limiting illness, but also, as their condition deteriorates, with the need for assistance with personal care.

Having to rely on others to meet personal care needs, which are private, can provoke strong emotions. Therefore, as a healthcare worker you will have to support the individual to come to terms with their loss of independence and to understand the emotions experienced in having their personal care needs met.

Emotions experienced may include:

- **Fear** – the individual may fear the unknown, losing their independence or losing control over their life and body. They may also be afraid of experiencing pain while personal care needs are being met. Individuals may fear the healthcare staff that will assist them, be afraid the healthcare staff will forget about them, or not meet their needs in a satisfactory manner. Also, new and unfamiliar aids or equipment can provoke fear in some people.

- **Feeling violated** – going to the toilet, washing and bathing are private matters and having to rely on strangers to meet these needs can lead some people to feel violated. A person who has been abused or who is painfully shy may feel violated when washed in intimate areas, or they may feel vulnerable, or feel as though they are being abused.

- **Helplessness** – being reliant on others to meet your personal care needs can provoke feelings of helplessness. As their health deteriorates and the individuals become more dependent, they may experience feelings of helplessness because they have to rely on others to meet their needs.

- **Loss of identity** – many people feel that in losing their independence and becoming reliant on others, they are not the person they used to be and they are unsure of their identity and their station in life. This can lead to lower self-esteem and a lower sense of self-worth.

- **Embarrassment and humiliation** – having to rely on others to meet your needs can be embarrassing and humiliating, especially when being assisted to use the toilet or wash intimate parts of your body. Some individuals also find it embarrassing to even have to ask for support, regardless of the type of assistance required.
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Promoting positive emotions
As a healthcare worker assisting individuals to meet personal care needs, you can promote positive emotions in the following ways.

- Treat the individual holistically, taking into consideration their physical, spiritual, psychological and social needs, not just concentrating on their illness.
- Involve the individual in care planning and review of care plans. With the individual's permission, family and other carers should be involved in the planning and delivery of care.
- Acknowledge and validate the individual's feelings.
- Promote independence and choice whenever possible; however, do not set the individual up to fail.
- Maintain the individual's privacy and dignity at all times.
- Value and respect the individual as a person, as well as their feelings, thoughts and opinions.
- Ensure you are familiar with and confident in your ability to use any aids or equipment the individual needs.
- Ensure you follow care plans and risk assessments when providing personal care.
- Check with the individual on the level of assistance they require, as their needs may fluctuate depending on their illness.
- Use time, when meeting personal care needs, to chat and build up a relationship. Remember to explain to the individual what you are doing, or going to do, and obtain their permission.
- Ensure you are prepared to carry out personal care activities; e.g. you have the toiletries ready, the bathroom has been prepared, the individual's choice of clothing has been laid out in readiness and any equipment or aids are to hand.

LO2 Be able to manage symptoms of end of life care

Demonstrate a range of techniques to provide symptom relief

Body language and non-verbal communication aid understanding
We all need to communicate with other people. Communicating our needs, wishes and feelings is vital – not only to improve our quality of life, but also to preserve our sense of identity. Pain and discomfort has many causes and it can manifest itself as a physical, psychological or emotional problem. Signs and symptoms of pain and discomfort can be many and varied, including:

- General body tension
- Verbalising the need for analgesia (pain killers)
- Complaining of pain
- Restricted movement/reluctance to move
- Pointing to/holding the affected part
- Swelling/deformity/inflammation
- Crying or other signs of distress
- Non-verbal signs, e.g. facial expressions, posture, etc.
- Agitation/confusion/irritability/fidgeting/nervous habits
- Sleeplessness (insomnia), disturbed sleep, restlessness
- Depression and/or anxiety
- Changes in behaviour – withdrawal or aggression
- Signs of fear or reluctance to seek medical advice – verbalising worries about ill health
- Light headedness, fainting, nausea or vomiting.

Evidence activity

Effective pain management and review
Prepare a list of actions you would need to take to ensure all aspects of pain management were effective and reviewed regularly.

Time to reflect

Failing to meet needs and preferences and not listening properly
How would you feel if your needs and preferences were not being met and you were not being listened to properly?
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It is important for healthcare staff to be aware of all aspects of verbal and non-verbal communication when communicating with individuals. An individual who is in pain may deny this verbally. However, their non-verbal communication may indicate otherwise; for example, they may grimace and flinch away from touch; also the tone of their voice may sound flat. For someone who cannot communicate verbally, non-verbal signs may be the only indication that a person is experiencing pain or discomfort.

Pain and discomfort can be alleviated using a variety of measures involving various members of the care team and other care professionals:

- Care professionals and care workers within the care team
- Nurses – specialist nurses such as Macmillan Nurses
- Doctors (GPs, physicians, surgeons, pain control specialists)
- Managers
- Physiotherapists will treat people following an operation, injury or stroke, using a combination of exercise and aids and equipment
- Chiroprists – will treat foot and nail problems which will relieve pain and discomfort for individuals, especially when walking or standing
- Dentist – to treat toothache, gum disease, neuralgia and infections (abscesses, etc.)
- Occupational therapists – can provide aids and equipment to increase independence and maximise the individual’s comfort
- Counsellors.

Medication

Over the counter medication does not require a prescription, and can be purchased from a variety of shops or a local pharmacy. Paracetamol, aspirin or ibuprofen can be purchased under a number of trade names for pain relief. Items such as cod-liver oil capsules (to help individuals suffering from arthritis), laxatives (for constipation) or antihistamines (for hay fever) can also be purchased.

Although a pharmacist will give individuals advice on safe use, generally we read the instructions and recommendations on the packet or bottle and use our own judgement for use.

Allopathic medication

This is orthodox medical treatment using drugs that treat and alleviate specific symptoms and disease. The medication, prescribed by a GP or other qualified practitioner such as a dentist or nurse, is obtained from the pharmacy and administered at times, and in doses, specified by the pharmacist. Medication would include:

- Analgesia – painkillers, e.g. morphine
- Laxatives – to relieve constipation
- Antihistamines – to relieve symptoms of allergies
- Anti-inflammatory – to treat arthritis and joint pain
- Antacids – to relieve symptoms caused by digestive problems
- Antibiotics – to treat infections
- Antidepressants and anxiolytics – to relieve anxiety and depression.

Medication administration

It is important that you recognise your role in the administration, monitoring and storage of medication. It is vital that medication is handled, stored and administered safely. It is suggested that you, as a care worker, undertake a recognised educational course to ensure you understand how to deal with medication safely. This is particularly relevant to care workers who are involved in the administration of medication within their care environment.

Group of drugs designed to relieve pain

An important aspect of end of life care is the relief of pain and control of symptoms. This may be achieved through the use of drugs. In order to be able to support the individual and the doctors and nurses trained in pain management, it is important that healthcare workers are not only familiar with their workplace policies and procedures, but also have an understanding of the methods and issues relating to pain and symptom control.

It is important for you as a healthcare worker to undertake suitable and appropriate training relating to the storing, recording, administering or disposal of medication to ensure that you know and understand how to manage it safely.

Figure 2.2 Medication can be obtained in a number of ways
The Medicines Act (1968) was the first comprehensive legislation on medicines in the UK. Together with any additional statutory legislation, it provides the legal framework for the manufacture, licensing, prescription, supply and administration of medicines. The Act classifies medicines into the following categories:

- **Prescription-only medicines (POMs)** – these are medicines that may be supplied or administered to a patient only on the instruction of an appropriate practitioner or a trained person who is listed as a nurse prescriber.
- **Pharmacy-only medicines (Ps)** – these can be purchased from a registered primary care pharmacy, provided that the pharmacist supervises the sale.
- **General sale list medicines (GSLs)** – these need neither a prescription, nor the supervision of a pharmacist and can be obtained from retail outlets. Generally, no medication should be administered without a prescription. However, local policies or patient group directions may have been developed to allow the limited administration of medicines in this group to meet the needs of the patient.

As well as being classified as POMs, Ps or GSLs, medicines can be classified according to the physical effects they have on the human system; for example, analgesics are a class of drugs used to relieve pain. The pain relief induced by analgesics occurs either by blocking pain signals going to the brain, or by interfering with the brain’s interpretation of the signals, without producing anaesthesia or loss.

**Importance of planning activities around analgesia**

It is important for healthcare staff to have a knowledge and understanding of which activities cause or may cause the individual pain. This will then enable healthcare staff to plan for these activities to take place after analgesia medication has been administered and taken effect. For example, an individual who experiences severe pain in the mornings should not be assisted to wash and dress until their analgesia has been administered and has started to take effect. Any activity may cause pain to an individual, so it is important for healthcare staff to assess which activities cause pain before developing the individual’s care plan.

**World Health Organisation’s (WHO) ‘Analgesic Ladder’**

WHO has developed a three-step ‘ladder’ (model) for cancer pain relief. If pain occurs, there should be prompt oral administration of drugs in the following order: non-opioids (aspirin and paracetamol); then, as necessary, mild opioids (codeine); then strong opioids such as morphine, until the patient is free of pain. To calm fears and anxiety, additional drugs – ‘adjuvants’ – should be used. To maintain freedom from pain, drugs should be given ‘by the clock’, that is every three to six hours, rather than ‘on demand’. This three-step approach of administering the right drug in the right dose at the right time is inexpensive and 80 to 90 per cent effective. Surgical intervention on appropriate nerves may provide further pain relief if drugs are not wholly effective.
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Key terms
The World Health Organisation (WHO) is the directing and coordinating authority for health within the United Nations system. It is responsible for providing leadership on global health matters, shaping the health research agenda, setting norms and standards, articulating evidence-based policy options, providing technical support to countries and monitoring and assessing health trends.

Time to reflect
21. Your experience of using complementary therapies
Have you had any experience of using complementary therapies? If so which therapy did you use and what impact did it have?

Complementary therapy, alternative therapy and integrated medicine
What is the difference between complementary and alternative medicine?
The terms ‘complementary medicine’ and ‘alternative medicine’ often are used interchangeably, but the two are different. Complementary therapies are used together with traditional western medicine. For example, you may take opioids to manage your day-to-day pain and use guided imagery to help manage a breakthrough pain episode. Alternative medicine is used in place of conventional medicine. For example, using a special diet to treat your arthritis instead of using medications recommended by a doctor is using alternative medicine.

Complementary techniques to manage pain include diet, exercise, biofeedback, massage, chiropractic care, acupuncture, and self-regulation techniques such as self-hypnosis, relaxation training, yoga, reiki (a natural healing process using the hands to tap a universal life energy) and Jin Shin Jyutsu (a process to balance the body’s energies to bring optimal health and well-being).

‘Integrated medicine (or integrative medicine as it is referred to in the United States) is practising medicine in a way that selectively incorporates elements of complementary and alternative medicine into comprehensive treatment plans’ alongside traditional methods of diagnosis and treatment. Integrated medicine focuses ‘on health and healing rather than disease and treatment’, viewing individuals ‘as whole people with minds and spirits’ (http://www.bmj.com/cgi/content/extract/322/7279/119?ck=nck).

Research and investigate
21. Find out about gate control theory
What is the gate control theory?

Gate control theory
The way in which we experience pain is very complex. All sorts of factors influence our experience, including our thoughts and feelings. For example, you will probably be aware that there are times when, even though you have pain, you are only dimly aware of it. This can happen, for example, when you are really engrossed in doing something interesting or having to face a situation that demands all your attention. A very good example of this are the stories you might have heard about wounded soldiers, who despite being seriously injured will continue in battle and not really be aware of much pain until after the danger has passed.

On the other hand, you will probably be aware of how in some circumstances your pain can feel much worse. Indeed, you may find that the more you think about your pain, the worse it can feel. Nerves from all over the body run to the spinal cord, which is the first main meeting point for the nervous system. In the spinal cord, you might imagine a series of gates into which messages about pain arrive from all over the body.

These gates can sometimes be much more open than at other times. This is important because it is through these gates that messages from your body pass towards your brain. If the gates are more open, then a lot of pain messages pass through to the brain and you are likely to experience a high level of pain. If the gates are more closed, then fewer messages get through and you are likely to experience less pain.
Examples of complementary or alternative therapies include:

- **Acupuncture** – an ancient system of healing developed in China and other eastern countries. Fine needles are inserted into the body at various pressure points to relieve pain or treat a variety of conditions.

- **Acupressure (Shiatsu)** – based on the same principles as acupuncture but without the needles, concentrating on meridians or energy lines.

- **Aromatherapy** – the systematic use of essential oils in holistic treatments to improve physical well-being. Oils may be heated in a burner or massaged into the body.

- **Chiropractic therapy** – specialises in the diagnosis and treatment of conditions that are due to mechanical dysfunction of the joints and their effects on the nervous system. Chiropractors use their hands to adjust the joints of your spine and extremities where signs of restriction in movement are found, improving mobility and relieving pain.

- **Counselling** – during counselling sessions the client is encouraged to explore various aspects of their life and feelings, talking freely and openly in a way that is rarely possible with friends or family.

- **Reflexology** (sometimes called zone therapy) – a therapy in which the nerve endings primarily in the feet are stimulated by specific massage techniques to effect changes in another part of the body and thereby create health and help overcome disease.

It is important that the client’s individual choice to use complementary or alternative therapies should be respected and planning for those therapies must be taken into account.

**Evidence activity**

**2.1 Approaches to symptom relief**

Investigate the approaches used in your work setting and find out how effective they are.

**2.2 Describe own role in supporting therapeutic options used in symptom relief**

It is important that carers provide support for people in the final hours of their life and every effort should be made to allow the person to express their needs and wishes and share their feelings and fears. This will include the implementation of therapeutic options for symptom relief.

**Pacing and spacing activities**

Pacing is a technique that a person can use to gradually increase their level of activity. If they have chronic pain, they might find that they have good days, when they can get on with things around the house or do something that they enjoy, and bad days, when they can do very little. As time goes on, some people find that they have fewer good days and more bad days. Pacing is all about breaking this pattern and gradually increasing what they can do. It should be possible to pace any activity, although in everyday life, we are not used to doing things gradually – we like to get things done quickly.

A person should start by choosing one or more activities that they want to be able to do, or be able to do for longer, for example, walking, sitting, standing, etc. If it’s the first time they have tried pacing, ask them not to be too ambitious. Encourage them to choose an activity that they find more difficult, but not impossible. Set a baseline amount of time in which they can easily and comfortably achieve the activity. Then ask them to practise that activity regularly, every day if possible, on good days and bad. Then gradually build up the amount of time they spend doing this activity, but never do more than they planned.

Write down the amount of time they spent on the activity on each occasion and this will help them to see how much they are improving.

Spacing involves breaking down an activity into manageable chunks and taking some time out between each chunk to rest and relax. By dividing up tasks in this way, the person can assess how they feel and how they are getting on with the task.

**Goal setting**

Chronic pain can affect lots of different aspects of a person’s life. Individuals may find that they have had to give up going to places or doing things that they used to enjoy because they are afraid that this may make them feel worse. Also, it may be a little frightening to think about starting something new. Goal setting is rather like pacing – a person can use it to gradually build up the activities that they do. It’s all about giving the person some control back, rather than letting the pain take over.

A goal is something that the person would like to achieve. It may be going to the cinema, walking the dog, or playing with their children or grandchildren. They could have all kinds of different goals, which can be either short- or long-term.
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There are four golden rules for setting goals:

1. The goal must be realistic.
2. It must be something you both can measure.
3. It should be the person’s own goal – don’t let someone else pick it for the person.
4. The person should not be too ambitious to start with – encourage them to pick something that’s important to them, but not impossible.

The first step is to decide on the goal. Then ask the person to think about all the things they need to do to achieve that goal. It might help to write this information down on a piece of paper. Say, for example, that their goal is to start driving their car again. There are lots of things involved in this:

- getting in and out of the car
- sitting in the driver’s seat
- turning their head to look in the mirror
- twisting to put on their seat belt
- moving the pedals up and down
- leaning forward over the steering wheel
- pulling the handbrake on
- changing gear
- opening and closing the door
- concentrating on the road
- looking to the side as they pull out of a junction.

Now look at each of these activities in turn: what do they have problems with? If, for example, they have a problem with sitting, they should start by gradually increasing the amount of time that they sit in the driver’s seat. To start with, they might only be able to sit for a minute or two, but after a few weeks, they should hopefully be able to build this up to 15 minutes, or so. They may also want to make practical changes, such as making use of back supports and wider mirrors.

It’s important to review their progress regularly – about once a week if possible – and rethink some of the person’s methods if they’re not working. Always tell the person to remember that each small step is an achievement in itself, and that lots of small steps can help them take one big leap.

Assertiveness/communication

People with chronic pain sometimes lose their confidence, finding it hard to express their needs. If they don’t express their needs clearly, this can increase their tension, which can increase their pain. So it’s important for them to communicate well and to be assertive. They can be encouraged to do this by following the simple tips given below:

- Be firm and say what they mean.
- Ask them to try not to complain, plead or be apologetic.
- Don’t shout or raise their voice, keep it calm and low.
- Make sure their message is clear, rather than expecting people to guess what they are getting at.
- Don’t tell people what to do, but explain to them why they are asking them to do something.
- Ask for help when they need it.
- When they are asking for something, say ‘I want’ instead of ‘I need’ and ‘I don’t want’ instead of ‘I cannot’.
- Ask them to try and be precise and to the point – don’t beat about the bush!

Research and investigate

What role would a carer play in identifying a person’s needs?

Stress

Stress and tension can make pain worse, so it’s important that the person learns how to cope with (or even avoid) stress. This involves knowing what it is and recognising when they are suffering from it. When undertaking activities they must be sensitive to the feelings that they are having, especially in relation to any pain that they may experience. Being aware of their emotions and taking action to calm themselves down and relax, despite the pain, will require practice and patience.

There are a number of ways of coping with stress, including:

- being able to relax
- having someone to talk to and confide in
- being able to find a practical solution to the problem, rather than worrying about it
- using pacing techniques and breathing exercises.