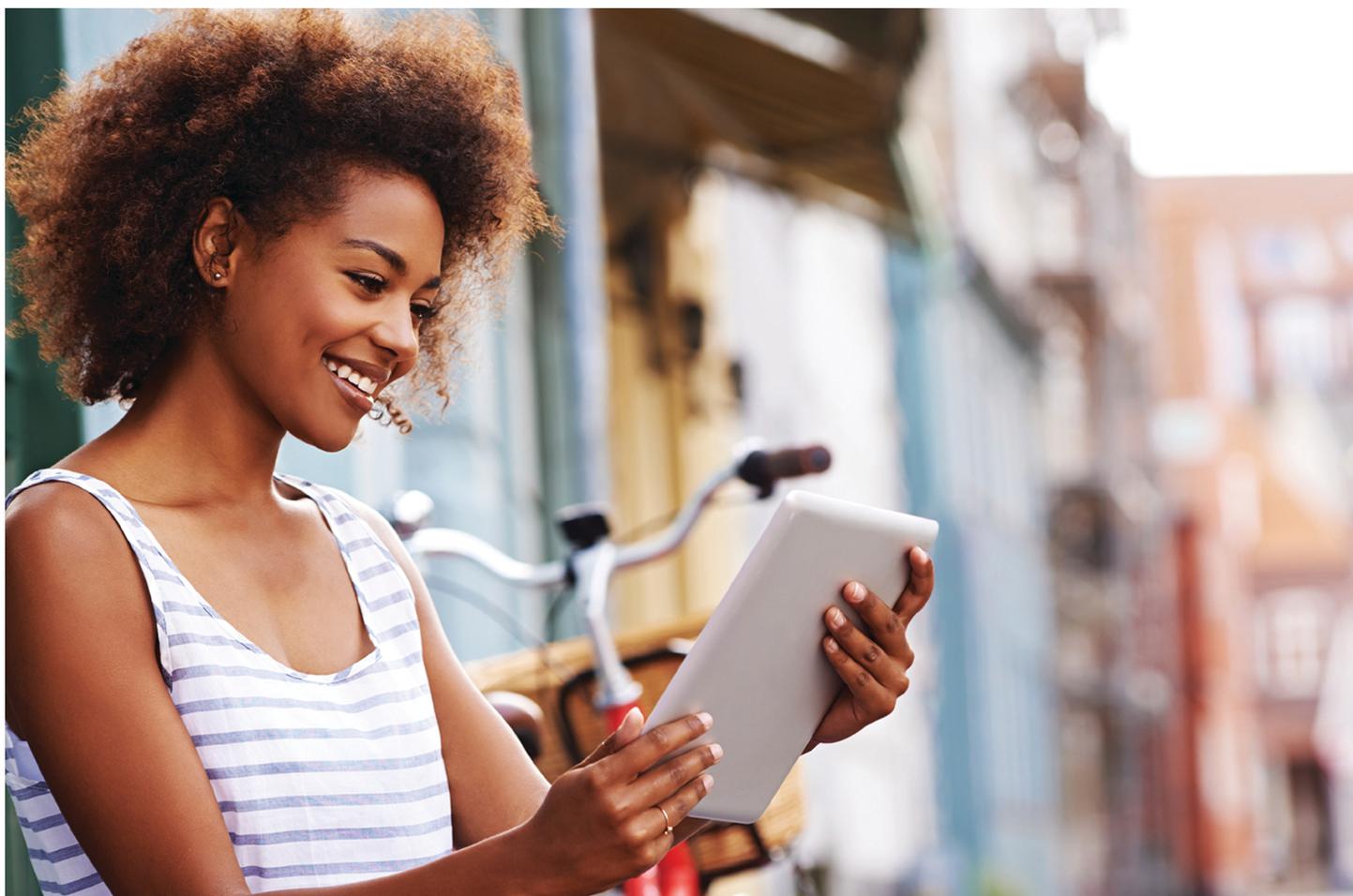




Palliative and end-of-life care



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Introduction

It is important to realise that everyone will die at some time – death is unavoidable. Being unavoidable, planning for death and discussing death with loved ones is a part of having a good death. It is not something that you as a carer should deny the cared-for person if they wish to talk about their wishes and fears. It is important that the cared-for person is given the opportunity to talk about their death but they should not be made to feel that they must. As either a paid carer or an unpaid carer there is only one opportunity to get end-of-life care right. You don't get a second chance for any individual cared-for person.

While the course is of value to all carers, the course team acknowledges that palliative and end-of-life care might be informal or carried out by paid care workers. While many people prefer to die at home, where their relatives care for them in their final months, weeks and days, they are often assisted by paid care workers. Some paid care workers specialise in palliative and end-of-life care.

An important consideration that is emphasised in this course is that carers need to take care of themselves as well as the person they care for. As you read, think about what support would be available to you from family or friends, or what support you might offer to family and friends should they be providing palliative or end-of-life care. You might find Section 1, Good communication (particularly having difficult conversations), and Section 5, Looking after yourself, helpful also.

In this section you will study palliative and end-of-life care. You will find out how to maximise a person's quality of life by employing the core principles that underpin good-quality end-of-life care. You look at how you can enhance the dying process to help the person have a good death.

Towards the end of the section you will reflect on a case study that brings together your learning and describes signs that someone is near to death. In the case study you follow Frank and Grace during Frank's final weeks.

At the end of the section there is a short quiz to test what you have learned about palliative and end-of-life care. On successful completion of the quiz you will earn a digital badge. This section is divided into five topics and each of these should take you around half an hour to study and complete. The topics are as follows:

- 1 **Palliative care** introduces palliative care as a treatment that relieves but does not cure a disease or an illness. Neither should it bring about the death of the person or delay the death. Its focus is on the physical, psychological, social and spiritual well-being of the dying person, and those close to him or her.
- 2 **Maximising quality of life** discusses how quality of life for a person receiving palliative care can be enhanced and personalised to the individual, while looking at how a special focus might be necessary if a child receives palliative care.
- 3 **End-of-life care** is part of palliative care for people who are thought to be in the last year of life. These people can be helped to have a good death, where what is meant by a good death is dependent on what matters to the person who is dying.
- 4 **Common core principles** describes a framework for how practitioners are guided to provide end-of-life care, while recognising that many practitioners who provide end-of-life care are not end-of-life care specialists.
- 5 **Approaching death** discusses what constitutes a good death as decided by the person who is dying, and recognising signs of death.

Learning Outcomes

By completing this section and the associated quiz, you will be able to:

- explain what palliative care and end-of-life care are
- describe how someone might have a good death and the signs of approaching death.

1 Palliative care

Palliative care is treatment that relieves but does not cure a disease or illness. Palliative care should not bring about the death of the person or delay the death. Its focus is on the physical, psychological, social and spiritual well-being of the dying person, and those close to him or her. It is often used to mean end-of-life care but, as you find out later, end-of-life care is a part of palliative care and so it is not the same as palliative care.

Activity 1

Allow about 20 minutes

Spend a few minutes thinking about what you understand by the term 'palliative care'. You might find it easier to reflect back on the experience of someone you know who died recently or someone who is currently having palliative care. If you have not experienced palliative care for someone you know, think about what you understand it should be.

Divide your thoughts into four criteria:

- 1 Physical: how is their body affected?
- 2 Psychological: what are they thinking about and how does it affect their emotions?
- 3 Social: do they have a social life or meet friends and family?
- 4 Spiritual: do they want to talk about the meaning of life or any faith they might belong to?

Use the box below to record your thoughts.

Provide your answer...

Comment

You know from the first paragraph in this topic that palliative care involves the physical, psychological, social and spiritual well-being of the dying person and those close to him or her.

The physical aspects of palliative care might include any medication and pain relief the person is prescribed, and body changes due to age, illness or inactivity. The palliative care focus would be on the physical comfort of the person: being at home or in a hospital is a key consideration, while pain management and hygiene are important for the dignity of the person.

Psychological aspects encompass both cognitive (thinking) and emotional effects that are important during palliative care. The person might be afraid of the process of dying, afraid of what to expect when dead, worried about how their spouse or family will cope or they may have long-standing arguments they want to settle. Palliative care would focus on communication, especially difficult conversations (you can find out more about difficult conversations in Section 1, Good communication); being given information and listening carefully to what the person wants in respect of funeral arrangements, for example, or any bequests.

The social aspects of palliative care include finding out about people the cared-for person would like to see or if there are some things the person would like to do. A palliative care approach might ensure that individuals the cared-for person cares about are informed.

Spirituality is often hidden in our culture but it does not mean it is absent. Opportunity should be given for the cared-for person to express their spirituality, whether it is through an established religion or through a less formal, although significant, part of the cared-for person's beliefs.

It's important to remember that palliative care is not confined to people with cancer, as is often believed. It might also be an approach that is used across all ages and a range of conditions, from respiratory disease to dementia.

A key objective is to improve the quality of life of the dying person and those close to them. You will now look at how quality of life can be maximised.

2 Maximising quality of life

A palliative care approach is more than easing the approaching death of an individual. It aims to improve the quality of life of a cared-for person who faces life-threatening illness, as well as that of their family. It does this by providing pain and symptom relief as well as spiritual and psychosocial support, from diagnosis to the end-of-life and bereavement. But palliative care also takes into consideration the preferences of people who, for whatever reason, don't want to know more about their approaching death.

A recent report for the Marie Curie Foundation revealed that most people favour quality of life over living longer (Dixon et al., 2015). Many people don't accept they are dying, or hope for a miracle cure to be found. Approaching death affects people in different ways and it is not unusual not to want to know how much time you have left.

Key aspects of palliative care are intended to maximise the quality of life for the person and their family and carers. It does this by working with people on controlling symptoms, offering practical assistance and giving emotional support. Palliative care takes a holistic approach as demonstrated by the World Health Organization's (2015) report on cancer care. You will look at key findings from this report in the next activity.

Activity 2

Allow about 20 minutes

Read what the World Health Organization (WHO) identifies as the key elements of palliative care.

Palliative care:

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten or postpone death
- integrates the psychological and spiritual aspects of patient care

- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patient's illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- will enhance quality of life, and may also positively influence the course of illness
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

(Source: WHO, 2015)

Think carefully about the findings above and answer the following questions:

- Is death regarded as normal?
- Is support only for the dying person?
- Is palliative care used instead of other forms of treatment?
- Does palliative care include bereavement counselling?
- Is pain relief the only aim of palliative care?

Provide your answer...

Comment

In palliative care, death is regarded as a normal part of life – after all everybody dies. Yet the support offered in a good palliative care approach supports the dying person and others who need support at this difficult time, with bereavement counselling being an example after the death of the person. It allows for different treatments to continue if they are in the best interest of the dying person, which include pain relief if necessary. If these were the answers you thought of, you are developing an understanding of palliative care.

The terms 'palliative care' and 'end-of-life care' are often used interchangeably. They do, though, have a differing focus, in which end-of-life care is part of a palliative care approach. There are of course many practicalities associated with end of life: making a will, dealing with immediate finances, adapting the house and arranging power of attorney are often necessary.

For family and other carers there might be additional issues, such as negotiating time off work with an employer, dealing with stress and adapting to the transition. It is also important to remember that palliative and end-of-life care is relevant across the lifespan. Older people die but so do people of all ages, including children.

2.1 Palliative care for children

There are particular issues if children are at the centre of a palliative care approach. The child might have a *life-limiting* condition for which there is no reasonable hope of cure and from which they will die. Alternatively, the child might have a *life-threatening* condition for which treatment in an attempt to cure may be feasible but can fail, such as when operating on a tumour.

Caring for any child with a life-limiting or life-threatening condition, and who is expected to die, will affect the whole family, from his or her parents, brothers and sisters, to the wider family members. Parents might find it hard to accept that their child is going to die and young brothers or sisters might not understand the enormity of what is happening.

In addition to the overwhelming emotional needs, many parents need help with practical support, which they might not have had time to consider. Special equipment may be needed in the house or a school located that can cope with the child's particular needs. The emphasis should be on discovering what the child can do, and not on what he or she is unable to do.

As with adults, palliative care for a child also encompasses end-of-life care. In the next part you will study end-of-life care as a part of a palliative care approach.

3 End-of-life care

End-of-life care is an important *part* of palliative care for people who are nearing the end of their life. It is for people who are considered to be in the last year of life, while acknowledging that this timeframe can be difficult to predict. End-of-life care aims to:

- help people live as well as possible and to die with dignity
- offer additional support such as help with legal matters
- continue care for as long as it is needed.

(Source: adapted from Marie Curie Cancer Care, 2015)

From what you have studied so far in this section you will know that holism and person-centred end-of-life care rely on understanding the dying person and their disease or illness. This depends on a good and detailed assessment that takes into account the person's wishes. In short, it helps lead to a good death.

Having a good death involves paying close attention to what matters to the person who is dying.

In the next activity you watch a video produced by the Social Care Institute for Excellence (SCIE) in which you follow the stories of two women who are approaching the end of their lives. The video follows specialists from a hospice who carry out holistic assessments and support the development of end-of-life care plans based on the cared-for persons' wishes.

Activity 3

Allow about 40 minutes

Watch the video [End-of-life care: what matters to the person who's dying](#).

As you watched the video, did you spot how the cared-for persons are included in the decisions about their end-of-life care?

Make brief notes about the plans they made.

Provide your answer...

Comment

You might have noticed that the intervention by the specialist helped provide some clarity for the family of the first patient. The second patient was initially reluctant to make plans about her end-of-life care but, with the help of a social worker, she did make plans for her end-of-life care and felt more confident and in control because she felt supported.

The video emphasises that while we will all die one day, we also only get one chance to get end-of-life care right. It is therefore important to listen and to act on what the person says. This might include explaining what is happening to family members and others who are close to the person. In this way, talking about what a good death can mean to the person can enhance the quality of their life as they near death.

The palliative care specialists from the hospice were very confident in the way they interacted with the two women in the video. This confidence was due to them being very able to do their jobs in difficult situations, but was also down to their understanding that end-of-life care was primarily about the cared-for people. The development of their relationships with the women was built on a particular approach to their role: being person-centred and holistic. This approach was underpinned by principles that guided how they interacted with the two women. These principles are explained in more detail next.

4 Common core principles

[Skills for Care](#) and [Skills for Health](#) are two organisations that offer development and workforce learning in the health and social care sector under the umbrella of Skills for Care & Development. The other organisations are:

- [Care Council for Wales](#)
- [Northern Ireland Social Care \(NISCC\)](#)
- [Scottish Social Services Council \(SSSC\)](#).

Children and early years employers should contact [Skills for Care & Development](#).

These organisations acknowledge that while people nearing the end of their life often need specialist care and support, non-specialists who participate in social care and health care increasingly find themselves working with people who are dying. For instance, family carers and caregivers in residential homes for older people might care for people at the end of their lives.

You might have noted that palliative and end-of-life care encompass some important principles: being person-centred and holistic, for example. In the next activity you study the seven core principles (Skills for Health and Skills for Care, 2014) that underpin end-of-

life care. These principles provide a framework for practitioners who deliver end-of-life care. Completing the activity will equip you with the necessary knowledge to understand the processes affecting people who are at the end of their lives.

Activity 4

Allow about 25 minutes

Read the seven common core principles below.

When you have finished, make a brief note of how each principle might affect end-of-life care for an individual.

Principle 1

Care and support is planned and delivered in a person-centred way with the person's priorities, including spiritual, emotional and cultural needs, guiding all decisions and actions.

Principle 2

Communication is straightforward, appropriate and timely and is delivered sensitively, taking account of the circumstances, needs and abilities of the person and their carers. Communication reflects an understanding of, and respect for, the person's cultural and spiritual needs.

Principle 3

End-of-life care is provided through integrated working, with practitioners collaborating to ensure seamless care and support at the point of delivery. Needs are met in ways that are appropriate to the person, rather than being service-led. Workers maintain ongoing communication so that care and support is properly co-ordinated and responsive to changing circumstances and priorities.

Principle 4

Good, clear and straightforward information is provided to people and their carers.

Principle 5

Regular reviews and effective communication ensure that care and support is responsive to the needs and changing circumstances of people, and their carers.

Forward planning, including advance care planning, facilitates well-coordinated, organised and delivered care and support.

Principle 6

The needs and rights of carers are recognised and acted upon. Carers are offered support both while caring and during bereavement. Employers recognise the ways in which workers are affected while caring for someone who is dying, and provide appropriate guidance and support.

Principle 7

Employers provide appropriate learning and development opportunities for workers to ensure that they are properly equipped to deal with people at the end-of-life. Workers are encouraged to take responsibility for their own learning.

(Source: Skills for Health & Skills for Care, 2014)

Provide your answer...

Comment

Briefly, the principles are:

- 1 person-centred care
- 2 communication
- 3 integrated working
- 4 information provision
- 5 planning and evaluation
- 6 rights for carers
- 7 proper preparation.

These principles reflect the skills that will enable you to provide care for the dying person that contributes to a good death.

So, how did you get on with identifying how the principles might affect the end-of-life care of an individual? Here are some brief notes that are possible answers to the activity question.

- Principle 1: The cared-for person chooses where to die – at home or in a hospital or hospice.
- Principle 2: The cared-for person is listened to carefully to find out their wishes and preferences.
- Principle 3: All the paid and unpaid carers talk to each other.
- Principle 4: Carers are open and honest with each other and the cared-for person.
- Principle 5: As needs change so does the care in response.
- Principle 6: Carers are cared for as well.
- Principle 7: Carers are trained and supported.

4.1 Holistic common assessment



Figure 1 A young lady holding the hand of an older lady

From what you have studied so far in this section, you will know that holistic and person-centred end-of-life care relies on understanding the dying person and their disease or illness. This depends on a good and detailed assessment that takes into account the person's wishes. In short, a good assessment of people's needs and preferences is more likely to lead to a good death than interventions that are based on assumptions about what an individual wants. The [holistic common assessment](#) (NHS National Cancer Action Team, 2010) is one tool that has been devised to meet the changing, complex and wide-ranging needs of people who are approaching death.

The holistic common assessment provides an opportunity to explore the individual's wider needs and identify how they might be met. By supporting choice and decision making the individual is able to identify what they want for themselves. By considering: Who? When? Where? and How? professionals are guided in delivering what the individual wants.

- Who should be assessed? The person who is recognised as moving towards the end of their life.
- When should they be assessed? Assessment should be seen as a continual process, where assessment is followed by reassessment.
- Where should the assessment take place? Anywhere that the person is comfortable and has privacy.
- How should assessment be carried out? The assessment should be conducted by a professional, who reviews previous assessments and aims for holistic care and potentially advanced care planning.

(Source: Extract adapted from NHS National Cancer Action Team, 2010)

5 Approaching death

One of the aims of end-of-life care is that the person has a good death. If possible, what constitutes a good death is decided by the person who is dying. You will now follow the case study about Frank and Grace. This case study has been divided into separate activities so that you can follow them as they prepare for Frank's death. In the first part you learn more about difficult conversations.

Activity 5

Allow about 15 minutes

Part 1

Read an excerpt that has been adapted from *Finding the Words* from the National End of Life Care Programme (Department of Health, 2011). It is about the worries that people and carers might have at the end of their life.

Key worries that people and carers might have at the end of life

- **Relationships** Am I still needed as a partner/parent/son/daughter or friend?
- **Existential/spiritual** Why me?
Why now?
What have I done to deserve this?
- **Physical/symptoms** Will I be in pain or experience any other physical symptoms such as incontinence, weight loss?
Will I lose control of my bodily functions?
- **Psychological** Will it change how people view me?
Will I be an outcast/avoided?
Should I tell people? How?
Will I lose control of my mind?
Do I really believe I am going to die?
- **Treatment** Will it cause any unpleasant side effects?
Will it prolong my life?
Will I be able to cope?
- **Practical** What financial arrangements do I need?
Who will look after the children/pets/parents/relatives?
- **Social/support** Who will look after me?
What extra help is there?
- **Dying** How long?
How ill will I become?

What will it be like?

(Source: Department of Health, 2011)

Part 2

Now read the case study about Frank and Grace and answer the questions that follow.

Case study: Frank and Grace Taylor



Figure 2 Frank and Grace embrace

Frank (64) and Grace Taylor (62) are very close. They have been married for over forty years. Frank is a retired civil engineer who has been receiving palliative care for bowel cancer for over a year. He is now receiving end-of-life care. He has secondary tumours throughout his body. There is little record of his health conditions prior to his diagnosis as he rarely visited his GP. He liked meat-based meals and drank spirits moderately at the weekend. Grace has been treated for depression recently.

Over the last month Frank has gradually grown weaker. Grace is adamant that she wants to be fully involved in his care. There has been much in-depth discussion of his approaching death. The time for a 'difficult conversation' has come to find out from Frank and Grace what is important to them towards the end of life.

For Frank an advanced care plan aimed to keep him at home in line with his and Grace's wishes. He was helped with personal care by carers from a local agency, and a community/home nurse visited daily to tend to the more technical elements of his care including medicines management.

- 1 What sorts of thing would you want to discuss with someone facing the end of their life?
- 2 How would you approach Frank and Grace about these matters?

Provide your answer...

Comment

There are some questions that are appropriate for the person whose life is ending and other questions that should be asked of their family or friends. Asking questions of other people might provide you with information that would enable you to give good-quality person-centred care; that is, care that the person near death deems to be good quality. Sometimes it might be difficult for people or their relatives to tell you what matters to them. Being sensitive, genuine and compassionate are vital at such times.

5.1 Advanced care plans

An advanced care plan is a structured discussion with patients and their families or carers about their wishes and thoughts for the future. It enables:

- better planning and provision of care to help them live and die in the place and the manner of their choosing
- clarification of peoples' wishes, needs and preferences
- delivery of care to meet these wishes, needs and preferences
- important yet simple conversations that can change practice and empower patients
- in-depth communication between patients and their families and loved ones.

(Source: adapted from Gold Standards Framework Centre, 2015)

Enabling advanced care planning is one intervention you can make with Frank and Grace. However, not all situations that occur can be planned for. One example is pressure sores or ulceration. Sometimes in end-of-life care the development of pressure sores is difficult to avoid due to skin changes that accompany ageing, failure of the circulatory system and disease progression. There are measures, though, that can be taken to protect and treat areas that are particularly vulnerable to ulceration. This is the case with Frank.

5.2 Signs that death is near

In the next activity you will continue to follow Frank and Grace in his last days. The National Council for Palliative Care website has a page on [Signs that death is near](#). Being able to recognise these signs can help relatives and others close to the person to prepare for what is to come and to say goodbye.

Activity 6

Allow about 10 minutes

Part 1

Read the National Council for Palliative Care list of indications that someone is approaching death.

As death approaches, you may see some or all of the following changes:

- **Physical changes**

In older people the skin can become paper-thin and pale, with dark liver spots appearing on hands, feet and face. Hair can also thin and the person may shrink in stature. Teeth can discolour or develop dark stains.

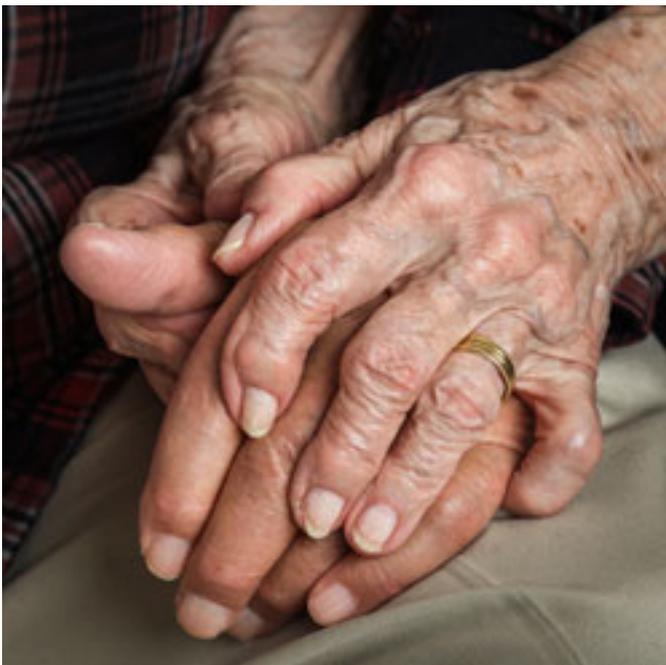


Figure 3 Hands can show physical changes as people age

- **Shrinking world**

The person's external world begins to diminish until the dying person no longer wants to leave the house or their bed and may not want to talk very much. Their mood, character and behaviour may change. For example, some may become more anxious. Others who have held atheist views may suddenly want to explore religious or spiritual teachings.

- **Increased sleep**

The person begins to sleep for long periods. This can be distressing for relatives, but it's important to understand that even the mildest physical exertion for someone approaching death can be exhausting, and for the moment all effort is being put into staying alive. Nearer the end, the dying person may increasingly drift in and out of consciousness.

- **Appetite reduction**

Appetite reduces as the body knows it no longer needs fuel to keep it going so those who are dying often lose their desire to eat or drink.

They can begin to lose weight, sometimes rapidly. It's important not to force food or drink onto someone who no longer wants it.

- **Expression**

There may be changes of expression where the person may start to talk about 'leaving', 'flying', 'going home', 'being taken home', 'being collected', 'going on holiday' or making some kind of journey. They may also begin to express heart-felt gratitude to their carers and to their family as a preparation to saying their farewells.

- **Special requests**

The person might make special requests, such as asking for something special, wanting to visit a particular place, or wishing to be surrounded by their favourite flowers. They may want to hear certain music, to have family photographs nearby or to make contact with someone who has been important in their lives. Some special requests might be difficult to fulfil, especially if they are unusual or illegal such as the choice of disposal of the body. It would be helpful to discuss unusual or illegal requests with a professional who might be able to clarify what can be done, and what alternatives might be considered.



Figure 4 Those being cared for may request to see family photographs

Part 2

Read about Frank's last days before answering the questions that follow.

Case study: Frank and Grace

Frank now prefers to stay in his bed most of the time where he is most comfortable. He has carers visiting three times a day to provide personal care. It includes repositioning him to avoid damaging tissue at pressure areas. His physical comfort has been given priority. At one stage it was thought he was retaining urine but since then he has been incontinent several times. He has also appeared to be in pain and has groaned in his sleep while trying to move.

As swallowing was obviously difficult for Frank, a syringe driver became necessary to ensure his morphine-based pain relief is effective. During a regular check on

vulnerable areas it is revealed that the skin at the bottom of his spine is looking red and very dry. Grace feels guilty about this as she has always observed and monitored the carers adjusting Frank's position in bed.

Frank had been in bed for eight days. During this time Grace was vigilant for any deterioration in his condition. His medication was increased so that he was drowsy most of the time. He drifted in and out of consciousness. When Frank woke for a few minutes he appeared disorientated and Grace was not sure that he knew who she was. He mumbled but his speech was slurred and unclear so Grace could not understand what he was saying.

He did, though, appear to be looking at something. She observed that the periods of unconsciousness were more prolonged. Frank's respirations were shallow and he sounded chesty. Holding his hand, Grace noticed that he was cold. By the time of his death, Frank had been unconscious for twenty-four hours. He had not taken any fluids or other nutrition during this time.

- In what ways did Frank show signs that his death was near?

Reread the indications and the case study if you need to, and make some notes in the box below.

Provide your answer...

Comment

Being most comfortable in bed is one sign that Frank might be near to death. Recognising signs of death can help make his last days and hours as comfortable as possible.

Many of the items in 'Signs that death is near' are reflected in what Frank and Grace experience. You would have been aware of some of the physical changes: Frank's skin, for example, and the shrinking of his world.

Frank slept more but this might have been as much to do with his medication as impending death. His appetite was probably reduced. Being drowsy, to feed him might have entailed further physical interventions that would make him less comfortable.

Frank seemed to have had no special requests at the last moments, although we cannot be certain. He appeared to want to say something. His change of expression, looking for something, might suggest a desire to make a special request.

Key points from Section 3

In this section you have learned:

- what palliative and end-of-life care are
- how palliative and end-of-life care can contribute to a good death
- ways to improve a person's quality of life as death draws near
- how someone can be supported to have a good death

- to recognise signs of approaching death.

Section 4 explores positive risk-taking. Risk assessment is usually considered to be solely about minimising risk to others. Studying this section will show you that positive risk-taking can bring additional benefits when the needs and preferences of the cared-for-person are taken into account.

Section 3 quiz

Well done, you have now reached the end of Section 3 of *Caring for adults*, and it is time to attempt the assessment questions. This is designed to be a fun activity to help consolidate your learning.

There are only five questions, and if you get at least four correct answers you will be able to download your badge for the 'Palliative and end-of-life care' section (plus you get more than one try!).

- I would like to try the Section 3 quiz to get my badge.

If you are studying this course using one of the alternative formats, please note that you will need to go online to take this quiz.

I've finished this section. What next?

You can now choose to move on to Section 4, Positive risk-taking, or to one of the other sections, so you can continue collecting your badges.

If you feel that you've now got what you need from the course and don't wish to attempt the quiz or continue collecting your badges, please visit the Taking my learning further section. There you can reflect on what you have learned and find suggestions of further learning opportunities.

We would love to know what you thought of the course and how you plan to use what you have learned. Your feedback is anonymous and will help us to improve our offer.

- Take our [Open University end-of-course survey](#).

References

Department of Health (2011) *Finding the Words*, Leicester, NHS National End of Life Care Programme. Also available online at

http://www2.westsussex.gov.uk/LearningandDevelopment/End%20Of%20Life%20Care/Finding_the_words_Workbook_web_1.pdf (accessed 11 March 2016).

Dixon, J., King, D., Matosevic, T., Clark, M. and Knapp, M. (2015) *Equity in the Provision of Palliative Care in the UK: Review of Evidence*, London School of Economics [online]. Available at

<https://www.mariecurie.org.uk/globalassets/media/documents/policy/campaigns/equity-palliative-care-uk-report-full-lse.pdf/> (accessed 11 March 2016)

Gold Standards Framework Centre (2015) *Advanced Care Planning* [online]. Available at www.goldstandardsframework.org.uk/advance-care-planning/ (accessed 11 March 2016).

Marie Curie Cancer Care (2015) *Palliative Care and End of Life Care* [online]. Available at <https://www.mariecurie.org.uk/help/terminal-illness/diagnosed/palliative-care-end-of-life-care#endoflifecare/> (accessed 11 March 2016).

National Council for Palliative Care (2014) *Signs that Death is Near* [online]. Available at <http://dyingmatters.org/page/signs-death-near/> (accessed 11 March 2016).

NHS National Cancer Action Team (2010) *Holistic Common Assessment of Supportive and Palliative Care Needs for Adults requiring End of Life Care*, NHS National Cancer Action Team. Available online at <http://www.nhs.uk/resources/publications/eolc-hca-guide.aspx> (accessed 8 April 2016).

Skills for Health & Skills for Care (2014) *Common Core Principles and Competences for Social Care and Health Workers Working with Adults at the End of Life* (2nd edn), Leeds and Bristol, Skills for Health & Skills for Care.

Social Care Institute for Excellence (SCIE) (nd) *End of Life Care: What Matters to the Person who's Dying* [online video]. Available at <http://www.scie.org.uk/socialcaretv/video-player.asp?v=holisticassessment> (accessed 11 March 2016).

World Health Organization (WHO) (2015) *Cancer* [online]. Available at <http://www.who.int/cancer/palliative/en/> (accessed 11 March 2016).

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Text

Activity 2: Extract from World Health Organization (WHO) (2015) *Cancer* [online]. Available at <http://www.who.int>

Activity 4: Text from <http://www.skillsforcare.org.uk> Skills for Health & Skills for Care (2014) *Common Core Principles and Competences for Social Care and Health Workers Working with Adults at the End of Life* (2nd edn), Leeds and Bristol, Skills for Health & Skills for Care.

Activity 5: Part 1: extract from Department of Health (2011) *Finding the Words*, Leicester, NHS National End of Life Care Programme