Macmillan
cancer relief

Foundations in palliative care

A programme of facilitated learning for care-home staff

1

First principles
Participant's workbook

Name

Supported by

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Workshop 1

Preparing to study palliative care

Module aims

Workshop 1 Preparing to study palliative care

To consider the meaning of palliative care and how it can be applied to the care of older people in care homes.

Workshop 2 Dying in care homes

To reflect on the experience of older people when they are admitted to residential care, and the losses and gains associated with admission.

Workshop 3 Dying in care homes and palliative care

To understand the dying process in older people and its relevance to palliative care.

Aim of the workshop

To consider the meaning of palliative care and how it can be applied to the care of older people in care homes.

Programme

Session 1.1	Introduction	**15 minutes**
Session 1.2	Small-group activity: caring for dying residents	**15 minutes**
Session 1.3	Feedback	**15 minutes**
Session 1.4	Discussion: what is palliative care?	**10 minutes**
Session 1.5	Small-group activity: hospice and care home	**10 minutes**
Session 1.6	Feedback	**10 minutes**
Session 1.7	Discussion: how can care homes provide palliative care?	**10 minutes**
Session 1.8	Closing remarks	**5 minutes**
Total		**1 hour 30 minutes**

Ground rules

The ground rules agreed in workshop 1 are:

1.

2.

3.

4.

5.

6.

7.

8.

9.

10.

Jim: a case study

At the age of 75, Jim is a relatively young resident of the Swallows Residential Care Home in the suburbs of the West Midlands, where he has lived for the past 2 years. Jim was transferred to the home following an admission to a local hospital after a stroke. He is very upset about losing his independence.

Before being admitted to hospital Jim lived alone after his wife's death and managed quite well. He has no surviving children – his son died shortly after birth and his daughter died of cancer 10 years ago. Jim's younger sister, Gladys, lives in Ireland. Before the stroke, they spoke to each other on the telephone every week, but they no longer do so.

Jim is very ill after a severe bout of flu and bronchitis. The bronchitis has not responded to antibiotics and he has spent the last 6 days in bed. He hardly moves, does not want to talk to anyone, and has to be encouraged to eat and drink. Jim is awake most of the night coughing, which disturbs the other residents. His doctor has told the staff that Jim is unlikely to recover and that he will probably die quite soon.

Notes

Definitions of palliative care

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.[1]

Palliative-care philosophy

The focus of palliative care is to enable dying people to be pain-free, dignified, and lucid during the terminal phase of illness. The aim of any treatment used is not necessarily to prolong life but to make it as comfortable as possible. The dying person is central to this process and is encouraged to retain control as long as is feasible. The intention is to provide the dying person and his or her family (or significant others) with a central decision-making role.

Palliative care is now a distinct medical specialty in the UK. It focuses on controlling pain and other symptoms, easing suffering, and enhancing the life that remains. It integrates the psychological and spiritual aspects of care, to enable patients to live out their lives with dignity, as well as offering support to families both during the patient's illness and their bereavement. It offers a unique combination of care in hospices and at home.

Palliative care arose out of a response to the needs of people with cancer, but it aims to promote good quality of life for everyone with non-curable conditions including older people with chronic and sometimes degenerative illnesses.

The aims of palliative care can be summarised as:

1. Provide symptom control and pain relief for the dying, without inappropriate treatment
2. Create a support system for dying people that provides individual social, emotional, spiritual, and practical care, and that enables the person to live as actively as possible and to exert control, independence, and choice, including participation in decisions, such as the decision to die at home or to transfer to hospital or residential care
3. Provide emotional, spiritual, and practical care for the dying person's family and friends during the illness and after death (bereavement care)
4. Establish a team that comprises the dying person, his or her family, friends, staff, and other healthcare professionals with good communication between the team members
5. Provide support and expert advice to those caring for dying people, such as hospital staff, GPs, social workers, psychologists, district nurses, clergy, dietitians, volunteers, chiropodists, and physiotherapists, irrespective of the place of care

Reference

1. The Open University. ***Caring for Dying People***. Workbook 2, course K260. Milton Keynes: The Open University, 2000;14.

Notes

Notes (session 1.5)

What can a hospice offer dying people that a care home cannot?

What can a care home offer that a hospice cannot?

Other notes

Next workshop

Module 1, workshop 2 (***Dying in care homes***) will take place on:

date

time

place

Your thoughts and reflections after workshop 1

Workshop 2 Dying in care homes

Aim of the workshop

To reflect on the experience of older people when they are admitted to residential care, and the losses and gains associated with admission.

Programme

Session 2.1	Introduction	**5 minutes**
Session 2.2	Small-group activities: leaving home – ageing and loss	**15 minutes**
Session 2.3	Feedback	**25 minutes**
Session 2.4	Small-group activity: transfer decisions	**10 minutes**
Session 2.5	Feedback	**15 minutes**
Session 2.6	General information: models of loss	**15 minutes**
Session 2.7	Closing remarks	**5 minutes**
Total		**1 hour 30 minutes**

Leaving home 1

It is 7pm. You receive a visit from the police who tell you that there is an unexploded bomb from the second World War in a nearby field, and that you must be ready to leave your house in the morning. You can take some belongings with you, but only what you can carry. You will be staying at the local church hall while the bomb squad try to defuse the bomb. You are told to leave your pets at home and that they will be taken to an animal shelter.

Which three items will you take?

What are your concerns?

Notes

Leaving home 2

You have spent all day at the church hall with no news. At 5pm you are shocked to hear a very loud explosion. The police arrive shortly afterwards to tell you that the bomb has destroyed all the houses in your street.

The police explain that you will not be able to return home, and that you will be moved to a very attractive communal living centre in the next town while a decision is made about future housing. You will have your own room, but will share all other facilities with 15 other people. Meals and laundry facilities will be provided for a set monthly fee.

You arrive at the centre. It is attractive and warm. The people there are quite friendly but you do not know anyone.

What are your thoughts and feelings?

Notes

Douglas: a case study

Douglas is a 74-year-old resident of Sunshine Hill Residential Home. He has lived in the home for 9 months and was admitted following the death of his wife. Douglas has little interest in life without his wife and home, and his health has gradually deteriorated.

The night-care assistant, Jane, has found Douglas on the floor of his room and thinks that he has had a stroke. He is pale, his skin is cold and clammy, he appears to be unconscious, and his breathing is very noisy and irregular. She is working alone and calls the home owner/manager, Mrs Redford, for help. Mrs Redford calls the locum GP, who wants to transfer Douglas to hospital. Jane and Mrs Redford disagree because they believe that Douglas is dying and that he should die in the home.

Notes

Loretta: a case study

Loretta is a resident of the Cedars Nursing Home, where she has lived for the past 4 years and where she has had reasonably good quality of life. One day, Loretta complains of severe chest pain. The nurse in charge of the home calls the GP who does not want to transfer Loretta to hospital because of her advanced age – she is 89. The nurse disagrees and argues that Loretta should be sent to hospital for immediate treatment. She believes that Loretta's age is irrelevant since her quality of life has been good up to now.

Notes

Christine: a case study

Christine has lived at April Lodge Nursing Home for 4 years. She has deteriorated since her admission; she has lost weight and suffers increasingly from indigestion and constipation. The community nurse has visited several times to treat the constipation, but Christine resists being referred to hospital for further investigation.

One night she is breathless and calls the night nurse for help. The nurse calls the GP. The GP wants to send Christine to hospital but she resists, saying that she will die in the hospital.

Notes

Models of responses to dying

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.[1]

The Kübler-Ross model[2]

Denial

People who are told that they are dying commonly respond with denial: 'No, not me, it can't be true!'. Denial is expressed in many ways. Kübler-Ross, for example, cites a woman who insisted that her X-rays had been mixed up with another patient's, and who saw several doctors in the hope of finding one who would give her a better prognosis.

Anger

Anger wells up after the initial shock. 'Why me?' is the characteristic response. Rage may be expressed against other people, such as doctors and family members, and against God, as if someone must be blamed for the overwhelming disaster.

Bargaining

The dying person attempts to make some kind of deal with fate asking for an extension of life until after a particular event, such as a world tour, a religious holiday, or the birth of a baby.

Depression

Depression occurs when a dying person experiences increasing weakness, discomfort, and physical deterioration, and when it becomes clear that recovery will not occur. Depression is associated with feelings of guilt and unworthiness, and thoughts and feelings filled with a sense of loss. The person may also experience explicit fear of dying and of a loosening of relationships with other people as he or she withdraws and becomes less responsive.

Acceptance

In this model acceptance represents the end of the struggle. As the person lets go, depression lifts. However, acceptance is not necessarily a happy state since it can be almost void of feelings. One dying person described it as the 'final rest before the long journey'.

Buckman's three-stage model of the dying process[3]

The table below is reproduced by permission of Oxford University Press.

Initial stage (facing the threat)	**Chronic stage (being ill)**	**Final stage (acceptance)**
A mixture of reactions which are characteristic of the individual and which may include any or all of: fear, anxiety, shock, disbelief, anger, denial, guilt, humour, hope, despair, bargaining	1. Resolution of those elements of the initial responses which are resolvable 2. Reduction of the intensity of all emotions 3. Depression is very common	1. Defined by the dying person's acceptance of death 2. Not an essential state provided that the dying person is not distressed, is communicating normally, and is making decisions normally

References

1. The Open University. ***Caring for Dying People***. Workbook 2, course K260. Milton Keynes: The Open University, 2000;85–8
2. Kübler-Ross E. ***On death and dying***. London: Tavistock, 1970.
3. Buckman R. Communication in palliative care: a practical guide. In: Doyle D, Hanks G, MacDonald N, eds. ***Oxford textbook of palliative medicine***, 2nd ed. Oxford: Oxford University Press, 1998;146.

Notes

Next workshop

Module 1, workshop 3 (***Dying in care homes and palliative care***), will take place on:

date

time

place

Your thoughts and reflections after workshop 2

Workshop 3

Dying in care homes and palliative care

Aim of the workshop

To understand the dying process in older people and its relevance to palliative care.

Programme

Session 3.1	Introduction	**5 minutes**
Session 3.2	Small-group activity: predicting death	**15 minutes**
Session 3.3	Feedback	**15 minutes**
Session 3.4	Small-group activity: dying trajectories	**30 minutes**
Session 3.5	Discussion: the relationship between predicting death and palliative care	**15 minutes**
Session 3.6	Closing remarks	**10 minutes**
Total		**1 hour 30 minutes**

Notes (session 3.2)

What advantages are there in being able to predict when a dying resident will die?

What factors make death difficult to predict?

Rose: a case study

Rose lived at Beech Hall for 3 years. During this time she suffered a series of severe bouts of bronchitis. In November, she developed pneumonia. Rose's family and the care-home staff thought that she would not live to see Christmas and began to spend as much time as possible with her. Apart from the chest infections, Rose's quality of life was good and her GP treated the pneumonia with antibiotics.

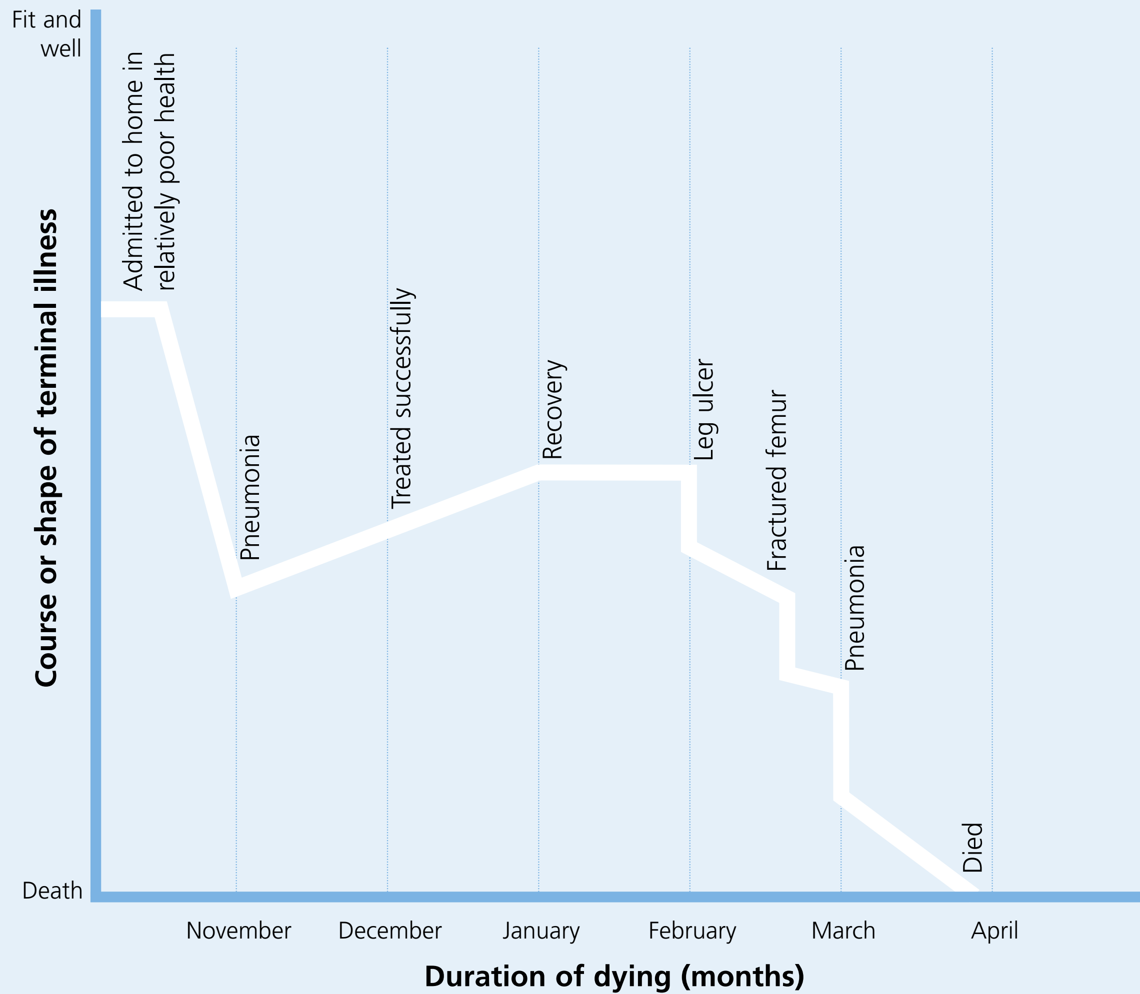
Although Rose slept through most of the festivities, by New Year she was well on the way to recovery. In February, however, Rose developed a painful leg ulcer and the pain was never adequately relieved.

One night, Rose fell on the way to the toilet, fractured her hip, and was admitted to hospital. Following surgery to repair the fracture, she again developed pneumonia and, despite efforts to treat the infection, she died a week later on 30th March.

Notes

Worked example of a dying trajectory

The dying trajectory shown below is based on Rose's story.



Deepak: a case study

Deepak was admitted to a nursing home following a stroke in June. He had no close family and few friends, was very depressed, and found it difficult to take part in the activities of the home. Deepak was in a lot of pain as a result of limb contractures caused by the stroke, and he often cried out in pain, especially at night.

While staff thought that Deepak would die, they did not think that he was actively dying. Three months later he was diagnosed with diabetes and the dietary restrictions made him even more despondent and withdrawn.

Two weeks later, he suffered another stroke. The GP agreed with staff that Deepak was dying and, as the staff in the home could cope with his care, that he should be kept at the home to die.

A fortnight later, staff were beginning to suffer from Deepak's intense care needs. They were surprised that he was still alive, although he was only semiconscious most of the time. Several nights later, Deepak could not be roused and he died in the early hours of the morning.

Notes

Lavender: a case study

Lavender moved to the Pine Trees Residential Home after her husband's death. She lived a relatively full life and was mobile and mostly self-caring. One of Lavender's main roles in the home was to welcome new residents, which meant that she had a wide circle of friends.

One day Lavender suffered a heart attack, which was a shock to everyone. She was admitted to the cardiac-care unit of the local hospital but was discharged back to Pine Trees after 2 weeks. She remained active but never seemed to recover fully. One night, during routine rounds, a night-care assistant found Lavender dead in her room. Everyone at the home was devastated by the news and extremely upset about the suddenness of her death and the loss of such a well-liked resident.

Notes

Blank dying trajectory

Fit and well

Course or shape of terminal illness

Death

Duration of dying

Plot the duration in hours, days, weeks, months, or years, as appropriate.

Next module and workshop

The next module is number ...., which is the .... module.

The title of the next workshop is ....

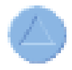
It will take place on:

date

time

place

Your thoughts and reflections after workshop 3



Certificate of attendance

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

This is to certify that

....

successfully completed

Module 1
First principles

on:

....

Signature:

....

Position:

....

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