

# End of Life Care DVD Training Notes

Lots of people think that End of Life Care is just about dying.

It is always hard to come to terms with death, no matter how often it is experienced, but making sure a good end of life is provided for those we are looking after, can make this easier. It's about the quality at the end, when someone is dying.....which can be just as important as the quality of life which we will cover in this training package.

In England and Wales every year, more than half a million people die. In every six deaths, five of these are people aged 65 or older. Deaths in care homes account for one in five of all deaths and inevitably staff in care homes will become involved in the care of someone who is dying.

If you are a careworker working in a residential care home, or working in the community, you may be the first person to discover that an individual you have been looking after, has died and this may be a distressing experience for you. You should receive training from your organisation regarding this and other colleagues will probably be able to support you, as they may have experienced this before.

Of course you may have recently experienced a death of someone in your family or close to you and this training could be upsetting for you. You might like to speak to your manager or supervisor about this.

You will need to know what your organisations' policy is when someone has died and a lot of the relevant information will be contained in the care plan.

During the course of your work you will be caring for people where English is not the first language. End of life care is sensitive to personal, cultural and spiritual values, beliefs and practices and encompasses support for families and friends.

Many different healthcare professionals can be involved in providing end of life care, depending on the individual's needs. Doctors and nurses within hospitals, hospice staff, GPs, district nurses and counsellors as well as social services, religious ministers, complementary therapists or physiotherapists can all play a part.

Most hospitals have specialist palliative care teams who can co-ordinate all these services. Working beside general staff, they deliver end of life care to patients and

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their families in hospitals, care homes, hospices and at home, assessing the need of the individual and obtaining the appropriate care for them.

They take a holistic approach, which means looking at all aspects of the individuals' wellbeing, including:

- **Physical:** managing pain, vomiting or coughing, tiredness, loss of appetite. Ensuring prevention of pressure sores.
- **Psychological:** providing emotional support to the individual and those who care about them, being able to give time to listen to them, and maybe sourcing counselling for someone if they are anxious or frightened.
- **Spiritual:** Most people will have spiritual needs and some, because of their religious or cultural beliefs, may have some practical things that need to be done. Others may ask "Why is this happening to me?"
- **Social:** finding the right support for a person's situation, for example, being cared for at home, as well as practical issues such as deciding where they wish to die, or perhaps getting their affairs in order

All care staff should know to contact their supervisor or manager, if after listening to someone who is nearing the end of their life, they feel that additional professional help or knowledge is required.

### When does End of Life care begin?

An individual may have days to live in which case the role of health care professionals is to manage the physical symptoms. They should also make sure that careworkers know the person is dying, to enable them to support the family through the emotional impact of death

In some cases, end of life care can begin the moment a person receives their diagnosis. This can be months or even years before they die, for patients with illnesses such as cancer, renal failure and AIDS related conditions.

On the other hand, someone who has an incurable illness but is expected to live for two, three or more years, may need a one-off intervention to help with pain or they may need help adjusting and accepting their diagnosis.

End of life care can also involve helping the individual to plan ahead. For example, making a will, thinking about where they want to be at the end of their life, and making their wishes about their treatment or funeral known to their loved ones and careworkers now. They may wish to let their family know which music they would

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like at their funeral, what sort of funeral, whether they would wish for flowers, or perhaps donations to a favourite charity in their memory. They may be unable to do this later and some people will experience a feeling of relief that they have taken care of things, rather than leave it all to their family.

Culture will of course play a large part in peoples' wishes for their end of life and subsequent funerals and you should be aware of this. This information should be contained within the care plan.

People are now able to make advance decisions in which they can refuse specific medical treatment or procedures and these can be legally binding. Care organisations will need to have detailed information regarding any such decisions, which are now covered by The Mental Capacity Act, which came into being in April 2007.

The NHS End of Life Care Programme, from which some of this information has been taken has three tools which are now being used in some care homes. The programme was set up to improve quality of care for people at the end of life and to help more people live and die in the place of their choice.

These three tools are:

### **The Preferred Place of Care Plan (PPC)**

This plan is a "record" of what choices the individual would like to make and will include details of where they would like to be when they die. The plan could include family details so that any new care staff involved in the care of the individual would be in full possession of all the necessary facts.

It focuses on improving collaboration with GPs who look after individuals in care homes.

For an individual who is nearing the end of their life, finding out about the options available, and talking with family or friends about their specific wishes, can help this decision be made.

Death can be a difficult topic to think or talk about, but if someone you are looking after has been given a terminal diagnosis it is a good idea to get them to think about what they would like, and then to share this with their family or friends.

Research commissioned by Marie Curie Cancer Care shows that 64% of people would choose to die at home but in reality only 25% achieve this.

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In **handout 1**, we have given some website addresses which you may find useful.

### ACTIVITY ONE

#### YOU MAY WISH TO PAUSE THE FILM NOW TO TAKE PART IN AN INTERACTIVE ACTIVITY

Some people feel more comfortable in a medical setting, others would rather be at home surrounded by familiar things. Wherever you choose to be, your pain and symptoms will be managed appropriately and counselling should be available if you need it. The team caring for you should also concentrate on ensuring that the end of your life is a time of dignity, calm and respect.

#### **Choices can be made, and choices can be changed at any time!**

If you choose to die at home, day-to-day care is usually provided through district nurses, some home careworkers and charity organisations such as Marie Curie Cancer Care can provide nursing care, too. You will be supported by your GP and may have access to a palliative care team or a hospice's at-home services.

Hospices can offer treatment of physical symptoms, psychological and spiritual support, and bereavement care. They can also provide a wide range of other services including complementary therapies such as acupuncture or massage therapy, art and music therapy and beauty treatments. They can care for people in a hospice building, care home or at home. Their services are usually free.

Care homes can be run by voluntary organisations, local authorities or for profit by individuals or companies. They don't usually provide 24-hour nursing care unless they are a nursing home, in which case there is a nurse on duty both day and night to support people who need it.

If the person you are caring for wants to find out what is available in the local area, you could talk to your local social services department, GP or district nurse, the palliative care team or the hospital doctor or nurse.

You should be aware of legislation and local policies in respect of equality, diversity, discrimination, rights, confidentiality and sharing of information when supporting an individual through end of life care

#### **What is End of Life Care?**

One definition of this is:

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End of life care is care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both the individual and their family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support. (taken from End of Life Care Programme – Building on Firm Foundations).

When individuals are coming to the end of their lives they need help and support to meet their needs, and the needs of those people close to them.

End of Life care should mean that the individual can:

- discuss personal needs and preferences with professionals. A care plan will record choices and preferences which will be accommodated wherever possible.

- receive coordinated care

- have rapid specialist advice and clinical assessment

- access high quality care during last days of life

- receive care which reflects dignity and respect

- access advice for their carers

The Department of Health have issued an End of Life Care Strategy which promotes high quality care for all adults at the end of life.

### Care pathways for the dying

The concept of a care pathway is helpful in understanding the needs of an individual as they progress through different levels and types of care. It considers all aspects of the journey on the pathway which will include care, investigation, intervention and information. It also determines which professional should undertake various aspects of care on the pathway.

The pathway for end-of-life care should include the following steps:

#### Step 1 Discussions as the end of life approaches

The individual should have the opportunity to discuss their personal needs and preferences with professionals who will support them. This means that those caring for an individual need training in how to determine when someone is approaching the end of life, and be skilled in appropriate and sensitive communication.

## **Step 2 Assessment, care planning and review**

Individuals in the end of life stage should have their needs assessed and recorded. There may be individuals who wish to make an Advance Decision whilst others may simply wish to record their wishes and preferences about care and where they would wish to die. The care plan should be subject to review by the individual, the care team and where appropriate out of hours emergency services.

## **Step 3 Co-ordination of care for individual patients**

The individual's care will be co-ordinated so that there are no distressing 'gaps' in the services. Everyone contributing should know their role and how they fit into the overall provision of care services. There should be rapid access to care services because the condition of the individual can change quickly and a suitable response can mean the difference between someone dying at home and being admitted to hospital.

Co-ordination of the care needs of individuals at the end of life and their carers should be considered at several levels:

- within an individual team
- between teams working within a single setting, for example a cancer team and a specialist palliative care team
- across organisational boundaries

## **Step 4 Delivery of high quality services in different settings**

There should be efficient delivery of advice and clinical assessment wherever the individual is living. For example there should be the same quality of care services to the person's home as there would be in a residential setting.

## **Step 5 Care in the last days of life**

The individual and family should be treated with dignity and respect. The Liverpool Care Pathway is a model which is increasingly being used by those providing end of life services. (more details follow)



Family members and close friends should also be supported, where possible when caring for the dying individual. They should have information about the individual's condition and the services available. Confidentiality is very important, so the Care Plan should show who information can be shared with.

## Step 6 Care after death

The individual's wishes about after death care should be carried out sensitively. There may be spiritual and religious needs and preferences which should be followed as far as possible. The needs of the family should also be considered, including information about bereavement counselling and support.

The **Liverpool Care Pathway** for the Dying Patient (LCP) is used by an increasing number of care settings, including hospices, hospitals and care homes. It was developed to bring the best of hospice practice into other care settings. It gives guidance on different aspects of care which include:

- good communication with individual and family
- planning to include social and spiritual needs
- anticipatory prescribing of medication for symptom control and pain
- care after death

Care settings wishing to implement end of life pathways should provide the necessary training for their staff

## Gold standard framework

The Gold Standards Framework (GSF) is a framework to enable a gold standard of care for all people nearing the end of their lives. The Gold Standard Framework aims to improve palliative care by ensuring that all relevant agencies work as a team to optimise the continuity of care

The standard identifies several key processes:

- identify individuals in need of supportive or palliative care
- assess their needs and preferences
- plan their care

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communicate across all relevant agencies throughout

The goals of GSF are to provide high quality care in the final months of life, with the following outcomes:

individuals are as symptom controlled as possible

individuals are enabled to live well and die well in their preferred place of care

advance care planning, information, less fear, fewer crises and admissions to hospital

carers are supported, informed, enabled and empowered

staff confidence, communication and co-working are improved

The GSF sets out 7 key tasks to be aimed for:

Communication

Co-ordination

Control of symptoms

Continuity including out of hours

Continued learning

Carer support

Care in the dying phase

### **The Preferred Priorities for Care (PPC), (formerly Preferred Place of Care)**

The PPC is a document which individuals hold themselves and take with them if they receive care in different places. It records the choices they would like to make and if possible where they would wish to die. Carers can read about what is important to the individual and ensure continuity of care. The document should be updated if anything changes. This plan gives the individual opportunity to draw up, together with care staff, an Advance Care Plan in accordance with the Mental Capacity Act.

The Gold Standards Framework website shows an example of an Advanced Care



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Plan.

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It is important to note that there is also a facility under the Mental Capacity Act to draw up an Advance Decision. This can be used by the individual to indicate their wish to refuse all or some forms of medical treatment if they lose mental capacity in the future. It cannot be used to request treatment. A valid Advance Decision has the same effect as a refusal of treatment by a person with capacity: the treatment cannot lawfully be given - if it were the doctor might face civil liability or criminal prosecution.

The Mental Capacity Act 2005 came into force in April 2007 and forms the legal basis for Advance Decisions.

From April 2007, to be valid an Advance Decision needs to:

- be made by a person who is 18 or over and has the capacity to make it
- specify the treatment to be refused (it can do this in lay terms)
- specify the circumstances in which this refusal would apply
- not have been made under the influence or harassment of anyone else
- not have been modified verbally or in writing since it was made

If you log on to [www.endoflifecare.nhs.uk](http://www.endoflifecare.nhs.uk) you will find a link to a detailed leaflet entitled 'Advance Care Planning: A Guide for Health and Social Care Staff'.

This document will explain how Advance Care Plans link to Advance Decisions within the Mental Capacity Act.

You will see from this DVD training package what a crucial part you can play in the End of Life Care process for the individuals you are looking after and also too how vital communication is.

During your induction training you will have learnt about the importance of communication, and in particular different types of communication together with some barriers to communication that you might come across in the workplace.

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YOU SHOULD NOW COMPLETE THE QUESTIONNAIRE