

## Death, Dying and Bereavement

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**Please complete the above, in the blocks provided, as clearly as possible.**

**Completing the details in full will ensure that your certificate bears the correct spelling and date.**

**The date should be the day you finish & must be written in the DD/MM/YYYY format.**

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N.B: We are aware that official practice is to use the terms “service users” or “people using this service” to describe those receiving care. We prefer the term “client” and use it throughout our training package.

### Key:



worksheet



important



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## Learning outcomes.

- Understand the requirements to protect the rights of individuals at the end of life.
- Understand factors affecting end of life care.
- Know how to provide support to individuals and key people during end of life care.
- Understand how to access support for the individual or key people.
- Know the action to take following the death of an individual.

## We suggest that the following Redcrier manuals will complement this manual:

Person Centred Approaches.

## Fundamental standards.

The fundamental standards are the standards by which CQC will inspect social care. The standards are based on the regulations from the Care Act 2014 and CQC have changed the focus for the purposes of inspection.

The fundamental standards are those standards that no care setting must fall below.

## The standards are based on five areas as follows:

- |                    |   |
|--------------------|---|
| <b>Safe.</b>       | People are protected from abuse and avoidable harm.   |
| <b>Effective.</b>  | People's care, treatment and support show quality of life and promote good outcomes, and providers should show evidence to prove it.                    |
| <b>Caring.</b>     | Care should be person centred involving dignity and respect, and compassion.  |
| <b>Responsive.</b> | Following correct working procedures as agreed by your workplace and as set out in the client's care plan.  |
| <b>Well led.</b>   | Management leadership and governance should ensure all of the above happens. Staff training should be recognised and openness and fairness be apparent. |

These areas are known as key lines of enquiry or KLOES. Each KLOE has a set of criteria which CQC use to check whether the fundamental standards are being met.

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The fundamental standards are as follows:

**Person centred care.** Ensuring that those receiving the care are at the centre of all decisions.

**Dignity and respect.** Providing the client with dignity and respect in all aspects of their care.

**Need for consent.** Asking the client's permission before carrying out tasks that affect them.

**Safe care and treatment.** Following correct working procedures as agreed by your workplace and the client's care plan.

**Safeguarding service users from abuse.** Following agreed working and safeguarding procedures and being aware of signs and symptoms.

**Meeting nutritional needs.** Being aware of dietary needs, working with the care plan, ensuring clients have the right equipment and conditions to eat.

**Cleanliness, safety and suitability of premises and equipment.** Carrying out required checks of premises and equipment, implementing cleaning rotas and carrying out safety checks.

**Receiving and acting on complaints.** Having a complaints policy and procedure in place that is accessible to all and act in accordance with the policy when dealing with complaints.

**Good governance.** Ensuring that all aspects of the workplace is overseen and policies and procedures are implemented and monitored regularly.

**Staffing.** Fit and proper persons employed.  
Fit and proper person requirement for Directors is followed.

**Duty of candour.** Relevant information must be volunteered to all persons who have or may have been harmed by the provision of services, whether or not the information has been requested and whether or not a complaint or a report about that provision has been made.

Our Redcrier manuals will provide your staff with training to support attainment of the fundamental standards.

# Death, Dying and Bereavement

## Introduction.

Around half a million people die in the UK each year, two thirds of these are likely to be over 75 and around 1 in 5 deaths occurs in a care home. As the population ages and admissions to residential and nursing care increase so will the need for staff to be aware of the particular needs of those reaching the end of their lives.

In 1900 around 85% of people died at home, now 58% of people die in a hospital and only 18% die in their own home. The increased medicalisation of death along with the reduction in deaths in childhood means that in general people have become distanced from it. Death has become a taboo subject which people are reluctant to discuss.

This lack of openness about death has led to an increased fear of it. Many people prefer not to think about it and pretend that it won't happen to them or their loved ones, they are then unprepared and may not get the death or funeral of their choice. By encouraging people to talk about death we empower them to make choices about where they will die, what treatments they will receive, who will be involved in their care and how decisions will be made when they are no longer capable.

What is a 'good' death? The definition of a 'good' death will be different for everybody; different cultures, religions and individuals will have their own interpretations. One thing most people have in common is a wish to die with dignity and to be treated with respect while dying and once death has occurred.

The government has recognised that there are significant shortfalls in the way that people are cared for at the end of their lives. It's well known that hospices provide a gold standard of care but they can support only a small percentage of those who die each year. With this in mind the government set a target of improving standards of end of life care in all settings. The National Institute for Health and Care Excellence (NICE) have produced the following guidance: *End of life care for adults* and *Care of dying adults in the last days of life*.

End of life care (also known as palliative care), was defined by the World Health Organisation as 'the active and total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families.'

It can be difficult to determine when end of life care begins; but it wouldn't normally start more than one year before death. The most likely to need end of life care are generally in the following categories:

- Those with days or hours to live.
- Those with advanced progressive conditions.
- Those at risk of dying from acute crisis arising from an existing condition.



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If end of life care is to improve for all, everybody who will be involved in caring for, and treating, people who are dying, and their families, will need training on the issues involved. A number of areas have been identified as important for good quality end of life care:

- Person centred care.
- Communication skills.
- Assessment of needs and preferences.
- Advanced care planning.
- Symptom control.

In addition to the above we need to include legislation and safeguarding, equality diversity and inclusion, practical and emotional support. Overall we need to ensure quality of life and make improvements where we can. This manual will cover each of these areas with clear examples of how you, as a carer will be involved in meeting the needs of clients at the end of their lives and also the support you, as a carer, need to ensure your health and wellbeing.

Remember that although clients may suffer the same illness no two deaths will ever be the same. At the end of life, as at all other times, clients are individuals and must be treated as such.

When a client dies you may feel a sense of failure, you may not be able to prevent a person dying but you can influence the how, where and when. If the client has died with a minimum of suffering, in a way that they wanted, then you have done your job.

As a person you may have very strong views about death and dying; as a carer you must make sure that you do not allow your feelings to influence the way you treat individual clients. You cannot impose your beliefs on those you care for; they must be cared for in a way that is appropriate to them, their feelings and their wishes.

Caring for people who are dying can be emotionally difficult, you may also find that you encounter situations that are new to you and you may be unsure how to deal with them. It's possible that at times you may need extra support to be able to manage your own feelings and to provide the best possible care. Do not be afraid to ask for help if you are struggling, your workplace should have policies and procedures in place for staff to follow.

As a carer your role will be to maintain a quality of life for clients. While recognising that they are dying you must encourage them to maintain independence and activity of body and mind for as long as possible.

## Gold standard framework.

End of life care is an important part of a carers support for their clients. The ageing population and increasing numbers of people with dementia has meant that care homes are supporting



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residents with a variety of conditions. This means that about a fifth of all UK deaths now take place within care homes. Because of this there is a need for care home staff to be trained to deliver excellent end of life care. Failure to provide a high standard of care at the end of life is not acceptable, it causes untold distress to residents and their families and leads to inappropriate admissions to hospital. The Gold Standard Framework was introduced to fill this gap.

## **GSF aims to:**

1. Improve the quality of resident care, in line with their preferences.
2. Develop your workforce for better collaboration and co-ordination of care across boundaries.
3. Improve outcomes and cost effectiveness, reduce hospitalisation and enable more residents to live and die with dignity and respect in their care homes.



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## Unit One

### Communication skills.

How do we know when it's time to discuss death? To overcome the taboo of death public awareness is being raised by schools, public bodies and employers. The aim would be for us to accept that dying goes hand in hand with living. Everyone should be open about their feelings, wishes and beliefs.

In practice most of us discuss death only when confronted by its reality, for example when a loved one dies or we have a health scare. Clients need to be encouraged to talk about issues surrounding death so that their wishes can be respected.

These discussions need to be:

- At the right time.
- In the right place.
- With the right people.
- Recorded appropriately.

There should be no pressure on clients to talk if they don't wish to and if information is being recorded and passed on this must be done sensitively and with due regard to confidentiality, gaining consent where appropriate.

Ideally clients will decide when they are ready to talk about issues surrounding their death and they will begin the conversations. However, it's not always possible to wait for this to happen and those caring for them will need to encourage them to talk. Death is a sensitive issue and must be handled properly; the following information is to help you improve your communication skills. It's important to recognise that you may not be the appropriate person for the client to be talking to. Essential information about health and treatment should be given by senior care staff or medical professionals. If clients have concerns or questions that you are unable to deal with, be honest with them and find someone who can help.

You may be uncomfortable talking about death; if this is the case you need help to overcome your problem. If a client tries to start a conversation about death and you dismiss it with 'let's not be gloomy' you've missed a chance to find out why they wanted to talk.

### The right time.

There are likely to be events that will create opportunities for end of life discussions; these may include:





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- Admittance to care.
- Death of a client or family member.
- Medical appointments, the time of diagnosis itself is unlikely to be appropriate as the client will need to get over the initial shock.

## The right place.

If, for example, a doctor needs to give the client important information about treatment options, or if they want to discuss their future care, then we need to ensure the environment is suitable.

The room should allow privacy so that information is kept confidential; background noise must be kept to a minimum and the client should be encouraged to feel relaxed and comfortable. Some people find hospitals and doctor's surgeries frightening so it may be necessary to arrange meetings in a familiar environment.

## The right people.

The following people need to be involved in discussions about treatment and care options:

- The client.
- Their loved ones.
- Medical professionals.
- Carers.
- Spiritual supporters, e.g. a minister or rabbi.

It is important that the client has control over what is discussed and who is involved; they may wish to keep certain information private. Unless the client is alone in the world they are likely to want people close to them to be involved in decisions; this may include partners (regardless of sex or marital status), children and trusted friends.

Under the terms of the Mental Capacity Act 2005, (see unit 2) if clients lose the capacity to make decisions for themselves their best interests must be taken into account. Anyone making decisions about their care will have a legal duty to speak to the people mentioned above and must formally record that they have done so. If the client has no family or friends they can be assigned an IMCA (Independent Mental Capacity Advocate) to represent them.

## Appropriate recording.

Some of the different documents that may be used to record the decisions, wishes and preferences of clients are discussed in more detail in unit 3. In general it is important to be aware that if end of life discussions are to be recorded the client must be aware of this and must agree to it. Documents should be filed appropriately to maintain confidentiality and should only be made available to relevant individuals involved in the client's care.

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While it will, of course, be helpful to have standard documents, formal and rigidly structured 'interviews' should be avoided. Information should be gathered in the course of conversations; the client may be encouraged to complete records in their own words or carers / family members / health professionals may write on their behalf.

## Good communication.

Talking about end of life issues requires sensitivity, tact and understanding. Every client is different; some will joke about death, others will refuse to talk about it at all and their right to do this must be respected.

To encourage clients to talk openly and honestly about their feelings, fears, hopes and beliefs the following ideas are good practice:

- Maintain a professional manner at work.
- Treat everyone with respect and dignity at all times.
- Build trust – respect confidentiality.
- Always be honest – if you don't know something don't make up an answer, go and find the information.
- Keep an open mind and respect clients' values and beliefs even if you don't share them.
- Promote and protect clients' equal rights.
- Listen to clients and make time to talk to them.
- Questions such as 'I'm not going to die am I' should not be laughed off; find out why the client has asked this, do they have particular worries that they would like to share.
- If bad news or important information about treatment options is to be communicated it should be done by someone who has the necessary skills, training and knowledge to deal with the situation appropriately.

When discussing sensitive subjects with clients maintain open, relaxed body language; keep your tone of voice neutral and use simple, clear language. When the client is speaking, use active listening skills (smiling, nodding, phrases like 'I see' and 'go on') show that you are interested and that you care about their feelings.

The following behaviours are to be avoided:

- Fidgeting, avoiding eye contact, mumbling – you will look as if you are uncomfortable with the subject.
- Glancing at your watch, looking towards the door – the client will think you don't have time for them.
- Using platitudes like 'I'm sure you'll be fine' or 'Oh, I'm sure you've got years yet.' – the client may have specific worries they want to talk about and trying to make light of the situation is likely to put them off talking.

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## Unit One Questions

1. Give an example that shows you are listening to someone.
2. Who should be involved in discussions about the treatment and care of a client who is dying?
3. Give an example of a time when end of life discussion may be appropriate.