



Manual for Caring Death and Bereavement

During this module you will be asked some questions to simply provoke thought and test your current knowledge please have a note pad or supervision workbook to hand to make notes. Your performance will only be measured on the answers you select when completing the knowledge test at the end of the module.

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Learning Outcomes

- How to support individuals and key people during end of life care
- How to access support for the individual or key people
- The action to take following the death of an individual
- The rights of individual at the end of life
- Factors affecting the end of life care

Complementary Manuals

- Equality, Diversity and Equal Opportunities
- Promoting Dignity and Compassion in Care
- Person-centered Approaches
- Mental Capacity Act 2005

Chapter One

Caring a 'Good' Death

“I’m not afraid of death; I just don’t want to be there when it happens.” — Woody Allen

The one thing we know for sure about life is that it has to end; you will experience the deaths of loved ones and you may have to support people you care for while they are dying. At the end of life we need to be treated with dignity and compassion and given the opportunity to die in a way we have chosen.

A ‘good’ death will be different things to different people; part of your job will be to find out what it means to your clients and to identify ways that their choices might be respected and achieved.

End of life care must be appropriate to meet the very specific needs that the person and their loved ones may have. Just identifying when end of life care is required can be difficult, for how do we define dying?

For example:

- Diagnosis of a terminal illness such as an aggressive form of cancer may occur years before death
- A potentially life-threatening illness or accident may be recovered from
- Death may occur ‘out of the blue’ without any chance to prepare or plan

As a general rule end of life care begins no more than 12 months before the person might be expected to die and must be responsive to changing needs within this time frame.

Respecting life

Although it is important to be sensitive to the mental and physical changes in the person who is dying, never lose sight of the fact that they are currently alive. Help clients to make the most of the time they have, don’t assume that they will want to sit around feeling sorry for themselves. Take your lead from the dying person, if they can face their present and future with humour and hope, so can you.

Doctors and health professionals can guide you but you must also make sure that you respect the individuality of the client. Get to know their preferences, habits and needs so that you can provide appropriate person-centred care.

To guide social care provision the government regularly reviews standards and approaches to all aspects of health and social care; their last guidance on end of life care – ‘The National End of Life Care Strategy’ – was issued in 2008 and identified 4 key areas requiring development:

- Communication skills
- Assessment and care planning
- Symptom management, comfort and wellbeing
- Advance care planning

This manual will look at each of these issues and help you to understand good practice in the care of people who are dying and their loved ones.

Person-centered measures

The Care Quality Commission believes that to appropriately meet people's care needs you must know and understand them as individuals and adapt care provision accordingly. Therefore, they promote a person-centred approach in which the individual becomes the most important part of a care partnership. Clients and care providers work together to find creative ways of maintaining physical and mental wellbeing and improve quality of life.

Person-centred approaches to care are based on several core values which include:

- Independence
- Dignity
- Privacy
- Rights
- Choice
- Respect
- Partnership
- Individuality

Note: Take a moment to have a think about some factors which may affect the choices people make about end of life care and funeral arrangements.

Person-centered arrangement

The better you get to know your client, the more comprehensive their care plan can be. When you find out information or observe behaviour that gives you an insight into an individual's needs, make an appropriate record and communicate your knowledge to colleagues. Ask client consent when sharing information and help them to understand why you want to tell other people.

While it's important to protect client confidentiality and to safeguard sensitive information; it's also important for everyone involved in a client's care to understand them and to know how to meet their needs in a way that is personally and culturally appropriate. For example, if you become aware that Mrs Jones doesn't participate in activities because she has hearing difficulties, everyone needs to know how to overcome these to allow her to join in; if Mr Kimber tells you that he loves listening to songs from the musicals because they remind him of his wife, this needs to be in his care plan.

A comprehensive care plan will be a great benefit when people reach their last hours or days; they may have become very physically and mentally frail and no longer be able to make their feelings known so this record tells those caring for them about their hopes and fears, their

sources of comfort, and the people that matter to them. Wishes and preferences recorded in care plans may not be legally binding but efforts should be made to respect them whenever possible to ensure an appropriate death.

Confirming a good death

All clients have the right to be treated fairly and appropriately by the people who care for them and this right is not affected by any physical or mental infirmity. Every client deserves to receive care that suits their personal, cultural and religious needs without discrimination or judgement. These rights are protected by legislation including the Equality Act 2010; the Human Rights Act 1998; and by the Mental Capacity Act 2005 (see Chapter 3).

Equality Act 2010

This Act simplified and strengthened existing legislation protecting individual's rights to fair, equal and non-discriminatory treatment regardless of their health, background, circumstances or beliefs.

The Act covers 9 'protected characteristics':

- Age
- Disability
- Gender Reassignment
- Race
- Pregnancy or maternity
- Religion / Belief
- Marriage or civil partnership
- Sex
- Sexual orientation

To meet the requirements of the Equality Act care providers must ensure that employees do not impose their own ideas or try to influence people by communicating their own religious beliefs or judging their lifestyle choices.

Clients' life choices and beliefs must be respected before, during and after death.

The Human Rights Act 1998

The Human Rights Act protects all of us from the actions of public bodies like councils and NHS trusts. Some rights are particularly relevant to the provision of care and they are summarised below:

- Article 2 – right to life
- Article 3 – protection from torture or inhuman or degrading treatment
- Article 5 – the right to liberty and security of person
- Article 6 – the right to a fair trial
- Article 8 – the protection of private and family life

- Article 9 – freedom of thought, conscience and religion
- Article 10 – freedom of expression
- Article 14 – freedom from discrimination

Collectively these rights mean that people should be protected from abuse and undignified treatment; they should not be unnecessarily restrained or have their freedom of movement restricted. They must be able to complain about the treatment they receive and be supported to understand and defend their rights.

People have the right to maintain a family life and have their privacy respected and they must be allowed to practice and express their religious beliefs.

People who are dying are at increased risk of abuse and of being treated in ways which threaten their dignity and privacy. You must protect them from harm and promote their rights when their physical and mental health deteriorates.

For good practical examples of how this Act might affect your life or the lives of your clients download ‘Ours to Own Understanding Human Rights’ from www.equalityhumanrights.com

Significant Communication skills

Excellent communication skills are essential for care givers who need to be able to discuss sensitive issues with clients and their loved ones. You must be able to:

- Talk to clients and others appropriately, without embarrassment or offence
- Encourage them to speak honestly to you
- Demonstrate tact, empathy and compassion
- Record appropriate information and know when and how to share it

Death cannot be ignored if clients are to be empowered to make their own choices. If it is not openly discussed there is a risk that the manner and place of their death will not be what they would have wanted. While death may be unpredictable, and some things may be beyond our control, we can put in place certain plans for what we would want to happen if circumstances allow.

All clients should be given appropriate information to help them to understand the reasons for discussing death, and the benefits of doing so. However, there should be no pressure to talk about dying, and care givers must be sensitive to the feelings of distress that the client may have.

There are different ways in which clients can make their feelings known including:

- Through formal planning sessions with care givers, loved ones and doctors
- In conversation
- Through comments about deaths within the home, in the news or on television
- By recording their wishes either informally, or as legal documents such as advanced care plans (see Chapter 3).

When the time is right to discuss death and dying with your clients you need to ensure that your conversations are effective and sensitively handled. Use active listening skills to show you are interested – use encouraging words and noises ‘go on’, ‘I hear you’; take notes if appropriate; maintain regular, not constant, eye contact and occasionally ask questions to check that you have understood

Do not be nervous or uncomfortable and don’t appear rushed or distracted; focus on the client and allow them to feel that they can speak openly and in their own time Do not overstep your boundaries by promising anything that it is not in your power to deliver and if your client has questions that you can’t answer don’t tell them what they want to hear, find someone who can answer them.

To create the right environment, minimize background noise; television, radios and general chatter and clatter will make speech more difficult to hear. If you are discussing personal information, make sure you are in a private space.

Position yourself in a way that makes the other person feel comfortable; make sure they can see you, stay at arm’s length to give them space and get on the same level i.e. if they are sitting, sit. If it is appropriate and acceptable, move closer and use touch to provide comfort and help the person to feel at ease with you. You could gently place your hand on their shoulder or forearm (avoid touching legs or any part of the body that might be considered ‘intimate’).

Always make sure that your facial expressions and posture are open and friendly; avoid using gestures which may be offensive to some people e.g. shrugs or hand signals. Speak clearly without slang, swearing or jargon to make it as easy as possible for the client to understand you.

Points of thought

These days death is increasingly separated from our everyday experience of life; instead of dying at home, most people end their lives in hospital. As our population ages and deaths in youth become less common it has become easier to protect children from the reality of death; it’s possible to reach a significant age without ever seeing a dead body.

While some changes are of course positive death is becoming a taboo subject which people find it increasingly difficult to talk about, make decisions about or deal with emotionally when it happens

If we fear and avoid death we may try to prolong life at any cost regardless of quality of life or the personal choice of the individual. Families have lost confidence in their ability to care for people who are dying and have no choice but to allow them to be cared for in hospitals. Many people avoid honest discussion about death, they use euphemisms like ‘gone to sleep’ or ‘passed on’ and try not to think about their own deaths or the possibility of someone they love dying. This can mean that when people do die, particularly younger people, their families and loved ones are less well equipped to deal with the grief and sense of loss and are at greater risk of becoming depressed

Chapter Two

Need analysis

The clients you support have 4 main types of need:

- Physical
- Psychological
- Social
- Spiritual

(The National Council of Palliative Care, 2006)

To be able to provide appropriate end of life care there must be comprehensive and on-going assessments of client needs which should be used to create care plans. These assessments must be holistic, that is, they should look at all aspects of the person, not just their physical needs.

In the last days and weeks of life people may develop very specific needs as a result of altered physical and mental states; support for this period of time will be discussed in Chapter 4. This Chapter looks more generally at the way in which we promote wellbeing for people who are expected to die.

Physical needs

On admission to care and at regular intervals afterwards clients' physical needs must be thoroughly assessed to ensure that they receive appropriate support.

Take a moment to think about how you and your colleagues record or assess clients' physical abilities, health concerns etc. Why not make some notes to remind yourself and assess your current knowledge or thinking.

There are many issues which must be considered when identifying clients' physical needs; they include:

- Pain – are they currently experiencing pain; do they have any health conditions that we might expect to cause pain now or in the future?
- Communication – can they communicate easily or do barriers exist? How can we promote communication?
- Chronic health conditions – how do we manage these to limit harm e.g. if they have diabetes, dementia
- Sight / hearing – do they have any sensory difficulties affecting their ability to interpret their environment, mobilise independently or communicate
- Continence – how can we assist independent toileting? Are there medical conditions to be treated?
- Mobility – what assistance does the person need to stand, walk etc.? Is equipment required?

- Eating / nutrition – is the client over or under weight/ Do they have any special requirements?
- Infection – is this client at increased risk of being infected? Are they currently carrying an infection?
- Skin integrity – is special care needed when assisting or to prevent pressure sores?

Care planning must be viewed as an ongoing process, not a one off task. It is impossible to find out everything you need to know during an initial meeting or even within the first few days following admission. It's important to allow time for clients to develop relationships with care givers and to feel comfortable sharing personal information.

Allowing time for monitoring will help you to identify issues which the client may be unaware of or unwilling to admit to, for example hearing problems affecting their ability to participate in activities or discussions. As you get to know a client you will become more sensitive to their changes in mood and behaviour and may develop more appropriate ways of supporting them.

By encouraging families and friends to be involved in their loved one's care you can get to understand more about them as a person including how best to communicate with them and motivate them.

Psychological Needs

It is impossible to separate physical and mental health; anything which affects one can also affect the other. If a person is physically unwell they are at greater risk of developing mental health conditions including depression and anxiety; while a person whose mental health is poor is more vulnerable to infection, illness and even injury.

The diagnosis of life changing or life threatening illness can cause a psychological response similar to that of bereavement. It may require a great deal of mental strength to come to terms with the possibility of death or with having to completely change the way you live your life. For example, a person newly diagnosed with heart disease may have been told that they could die at any time and that in order to avoid this they must improve their diet and lifestyle.

Grief responses may include shock, denial anger, depression fear or regret. The person may deal with their problems by pretending that they don't exist or they may become distressed about things they wish they hadn't done or angry that life has been unfair. The person may internalise their feelings and become withdrawn and uncommunicative or they may throw themselves into activities and social situations which keep them too busy to think.

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While caring for people who are dying you must allow them to express their feelings without fear of judgement or reprisal. They need to feel able to open up to people around them. It's also important to remember that the clients' loved ones will also be affected and they may also need emotional support.

By treating clients with dignity and respect you can help to maintain their mental wellbeing and also demonstrate to their friends and family that they are receiving the best care and support possible. This may help them to feel comforted in the time leading up to and after death

As a care giver supporting a dying person you need to feel that you are doing all you can to make a 'good' death possible. You need to know that the clients' needs are being recognised and met and that you are doing all you can to protect them from physical and mental pain or discomfort.

When you know that someone is dying you need to be honest and open but also compassionate and tactful. Through discussion with the client you may identify needs and goals which require immediate action to achieve within the time available. If the person's death comes more suddenly than expected a sense of unfinished business may make it harder for their family, friends and care givers to deal with their loss.

Social Needs

Have a think about and even takes some notes on some of the opportunities that may be available for your clients to experience social interactions

There may be barriers which make it difficult for clients to maintain relationships; these must be overcome in order to protect their mental wellbeing. Barriers may include:

- Mobility problems
- Communication difficulties
- Distance from family, local facilities etc.
- Physical and mental health conditions

Clients' emotional and physical health will benefit if they are supported to have a range of social interactions. Unless people want to be alone they should be protected from loneliness by regular contact with care givers, other clients, family and friends. If their loved ones are far away, or if they have outlived them, extra effort should be made to ensure that they still have regular opportunities for conversation; volunteers may be able to help with this, or clients can be encouraged to form their own support groups. In some homes the more physically able clients organise rotas for spending time with less mobile individuals who may find it difficult to spend time in the lounge or dining room.

Some people find it difficult to talk to individuals who are dying, they don't know what to say and are worried about causing offence. You may need to create a sense of 'normality' for the dying person, talk to them about everyday things and help them to keep up to date with what's happening in the world around them.

At the end of this manual you will find details of groups who can support you in meeting client needs, either because they have a volunteer network, or because they run clubs and support groups within the local area. If it would be challenging to transport your clients to meetings, why not consider hosting coffee mornings for the community?

Spiritual Needs

While not all of us have a religious faith spiritual needs are almost universal.

The following questions may help you to identify your own spiritual needs and can be used to improve your knowledge of your clients:

- When you feel sad what makes you smile?
- How do you relax?
- What are your fondest memories?
- Where do you feel most comfortable
- Who do you turn when life gets difficult?

Spiritual needs may be met by creative activities, acts of worship, books or chances to interact with animals or the natural world. Memories can be of major world events or of the smallest everyday happening such as a baby's smile. People may choose to be guided by priests, rabbis or imams or they may find their own ways to feel fulfilled and connected to the world around them.

To support clients' spiritual needs you may consider the following:

- Provide equal access for religious observance - you may provide transport to services, create space within the home for worship, celebrate festival and, invite representatives of different faiths into the home
- Support trips out to parks, beaches and woodland; create special spaces in outside areas, put in bird boxes or tables or grow wild flowers; at the very least bring flowers and greenery into the home
- Create opportunities for contact with animals – it may be possible to keep cats or other pets within the care environment, but, if this is not possible there are individuals and charity groups who can bring all kinds of domestic animals in to be petted. Some homes even allow donkeys onto the premises.
- Theatre trips, music appreciation sessions and art classes can all be worthwhile.
- Books are a source of pleasure to many, but the benefits of reading are easy to overlook. If people are experiencing sight problems or have difficulty physically holding a book they may be missing out on an activity which could provide them with an escape from their everyday problems. Libraries provide reading material in different formats and can cater for most needs; contact your local library and find out how they can help.

Chapter Three

Assisting to decide

As long as they are mentally competent to do so people have the right to make choices about all aspects of their lives; people who are dying may become mentally and physically vulnerable to having this right removed from them by the actions of those close to them. You have a duty to protect your clients' right to make choices and to support them to ensure that their needs are met in a way that they want them to be.

If clients are not protected they may be taken advantage of, ignored, neglected or abused. Relatives and care givers may try to impose their own beliefs and values ignoring the individuals' wishes regarding personal care, food or funeral arrangements. Treatment that does not respect an individual's values and beliefs may compromise their rights; strip them of dignity and lead to discriminatory practice

Dying people may experience financial abuse; relatives and care givers may put pressure on to amend wills or may take advantage of physical dependency to steal money or objects of value. If people lose the ability to communicate verbally and are not appropriately assessed they may be left to experience uncontrolled pain or discomfort They may also be at risk of receiving medical treatment that they didn't want because doctors make the decisions without reference to their religious, ethical or personal beliefs

Your client's rights to make choices are protected by legislation and the duty of care you have to safeguard them from harm. The Equality Act, The Human Rights Act and The Mental Capacity Act are all relevant and you should understand how risk assessments are used to keep clients safe while maintaining their freedoms.

Arrangement for advance care

By encouraging advance care planning care providers give clients the opportunity to make important choices about their future while they retain the mental capacity to do so. This type of care planning aims to identify and record clients' wishes about the following issues:

- Where they would like to die
- Who they would like to be with them when they die
- Their beliefs, values and goals
- The type of care and treatment they would like, or wish to avoid
- How they would like their body to be treated after death
- The kind of funeral they would like

Advance care plans need to be appropriately documented and made available to anyone who will be involved in the client's care or treatment. This might include paramedics, doctors and specialist nurses as well as the staff providing day to day care. Planning discussions should involve the client, their care providers, and any friends and family that the client wishes to involve.

Up to date records of clients' wishes and preferences help care providers to make informed decisions based on 'best interests' if the client is unable to make decisions themselves.

This may be necessary if the following situations occur:

- The client becomes unconscious and requires treatment
- The client's mental capacity deteriorates and affects their ability to reason or understand information
- The client is under the influence of alcohol or medication reducing their mental capacity
- The client is experiencing severe depression and lack the motivation to make decisions or take actions to meet their own needs

The Mental Capacity Act 2005

It is now law that ALL adults must be assumed to have the capacity to make decisions and take actions for themselves unless after being provided with appropriate support and information it can be shown that they do not. If it is decided that a person lacks capacity then decisions must be taken in their best interests and they must be involved in the process as far as possible.

The Mental Capacity Act 2005 was designed to protect the rights of potentially vulnerable adults who might otherwise be prevented from making their own choices and decisions.

The Act is based on five key principles which together ensure that individuals are respected as competent adults; given every opportunity to make their own decisions and choices; treated fairly without prejudice or discrimination and supported to be as independent as possible.

The statutory principles

1. A person must be assumed to have capacity unless it is established that he lacks capacity
 2. A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success
 3. A person is not to be treated as unable to make a decision merely because he makes an unwise decision
 4. An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests
 5. Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action
- (Mental Capacity Act 2005 Code of Practice)

Effective participation

Central to the provision of person centered care is the principle of active participation. By enabling clients to actively participate in making decisions about all issues that might affect them you help to ensure that they are having their needs met in a way which suits them.

All clients are to be encouraged to take an active role in planning for their own care needs, identifying ways in which their mental and spiritual wellbeing can be supported and influencing changes to the environment in which they live. Active participation ensures that needs are met in ways that suit individuals' cultural, religious and personal requirements. They are more likely to feel empowered to voice their own opinions and know that these will be given due consideration.

Clients who are supported to participate in all aspects of care planning and provision can influence their care environment and practices and they can feel confident to speak out about practices that they feel to be discriminatory or otherwise abusive.

The following resources might be helpful if you want to find out about personalisation and active participation:

- www.scie.org.uk
- www.skillsforcare.org.uk
- Approved Care Training manual 'Person-Centred Approaches to Care'

Advance treatment refusal decision

An 'advance decision to refuse treatment' is a legal document used to record decisions about medical care. These can be used by people who would prefer not to have treatments which may be experimental or invasive or which cause significant side effects or prolong discomfort and pain.

In order to be legally binding these documents must be up to date and specific about the conditions and treatments that they apply to. If doctors have reason to believe that advance decisions do not apply or are no longer valid they can ignore them and make a 'best interests' decision instead.

If the person has maintained the capacity to make their own decisions, advance decisions will not be used.

Note: If a person has said anything to suggest that they have changed their mind this casts doubt over the validity of the document; for this reason, it is best practice to regularly review decisions and to sign and date documents.

Do Not Resuscitate (DNR)

People who are experiencing significant physical pain or discomfort, or who have a poor quality of life, may prefer not to be resuscitated. If, for example, paramedics are called out, you must have signed confirmation that the individual does not wish to be resuscitated or they will go ahead and do it anyway.

All clients should be able to make their own choices and these need to be recorded and communicated. You must not make assumptions about a client's quality of life; everyone must have free choice without being influenced by the feelings of others; they must not feel that they are a burden.

Decisions must be kept up to date but discussions should be handled sensitively – asking someone ‘would you like to be resuscitated’ on a weekly basis would be insensitive and unnecessary, assess opinions when clients are admitted and then reassess whenever their situation changes. If there is any doubt about the person’s wishes resuscitation should be attempted.

A blanket policy not to resuscitate clients will be against their human right to life.

Chapter Four

Symptoms management

Although end of life care may begin some months before someone is expected to die, as people enter their final days and hours certain common symptoms are likely to become more severe and careful and sensitive management is needed to help them feel as comfortable and free of anxiety as possible.

Complications during this dying period may include:

- Pain
- Breathlessness
- Nausea and vomiting
- Delirium
- Anxiety

At this point all the information that you have gathered about this client should be reviewed and assessed; anything that is relevant to the provision of care for their last hours should be highlighted and used to plan treatment.

Ensure that you maintain the client's dignity; always treat them with compassion and in a way that shows respect for their essential humanity. Talk to them, explain everything you do and ask for permission regardless of whether they can respond or not. Remember always that you have to act in a way that is appropriate to their personality, values and beliefs, not your own.

Get professional support whenever appropriate and necessary; by working as a team with doctors, specialist nurses etc. you can reduce the likelihood of the client ending up in hospital. Also remember to support social needs; family and loved ones should be able to stay with the dying person for as long as they want to and are wanted.

Pain

For most people a 'good' death should be as pain free as possible; the reasons for pain and the types of pain which may occur are many and varied. Different people experience pain in very different ways; some can cope better with it than others; some may view expressions of pain as a sign of weakness.

Individual's pain must be assessed and appropriate treatment arranged. Painkillers may need to be ordered in advance so that they are available when they are needed. The client's doctor will be able to help with planning and with identifying the most suitable medication.

Doctors should reduce all medication to what is essential to prevent pain and discomfort and thought should be given to the way these medications are administered to reduce client distress.

If clients are not able to communicate they must be carefully monitored for signs of pain or discomfort and also assessed for the type of pain they might be expected to be experiencing based on their diagnosis and general physical health. It may be necessary for clients to be prescribed a combination of different types of painkiller to be effective and to provide constant relief.

All painkillers may cause side effects which should be monitored and treated if possible; sometimes it may be necessary to weigh up the possibility that medication may cause life threatening effects against the need to alleviate pain and suffering. This can be an ethical dilemma as doctors know that certain treatments may hasten death but also recognize that death is imminent anyway.

As a care giver it is important that you understand the risks and benefits of any medicines you administer, that you administer them according to doctor's instructions and that if you can give medication 'as required' you do so in the best interests of the client to manage pain, not to shorten life.

Breathlessness

One of the more upsetting and noticeable symptoms experienced at the end of life is difficult and distressed breathing. Pain and anxiety can increase breathlessness so care must be taken to control pain and calm fears.

Appropriate medication is available; to help you can ensure that the client is positioned comfortably supported by plenty of pillows; that the room is well ventilated and kept at a comfortable temperature and that any irritants such as strong smells or dust are dealt with.

Playing the client their favourite music or giving them a gentle hand massage may help to reduce their stress.

Nausea and Vomiting

Clients should be assessed to determine the cause of any nausea or vomiting, it may be necessary for doctors to change medication they are on or to prescribe something to manage these symptoms.

Delirium

Delirium is a sudden deterioration in mental state which causes significant confusion and agitation. Affected clients may experience hallucinations and paranoia and they may be extremely distressed and fearful. These symptoms of delirium can be distressing for the dying person's loved ones who should be given information about the condition and supported to maintain contact with them.

Triggers for delirium include medications, infections, constipation and pain so it is important that clients are assessed and underlying causes treated where possible.

Anxiety

Anxiety is common in people at all stages of end of life but may become more noticeable and significant during the dying phase. To protect people from effects such as panic attacks and increased breathlessness it will be necessary to find ways of reducing their stress and making them feel comfortable.

Good understanding of clients' emotional, social and spiritual needs will help to identify suitable ways of treating their anxiety.

- Ensure privacy, peace and quiet
- Support spiritual needs – opportunities for prayer or meditation; soft music
- Support emotional needs – through talk and appropriate touch ensure the person knows they are cared for and will be treated with dignity, compassion and respect

Discomfort reduction

As an individual's world shrinks to the room they are in they may become increasingly sensitive to what would otherwise be minor irritations. This sensitivity combined with mobility problems can increase the risk of pressure sores; because regular repositioning may be unnecessarily disruptive you must ensure that bedding is wrinkle free and as soft as possible. Natural fabrics, specialist mattresses and sheepskins can all be used to improve comfort.

Final hours care

When it becomes obvious that a client is entering the final hours of life their loved ones should be informed (as previously agreed with the client) and care givers should be mindful of their needs as well as the clients. A quiet room and occasional refreshments may be appreciated.

The client's comfort should be care givers' main concern. Offer regular sips of water, keep their mouth clean and moist, make sure that the room is quiet, calm, softly lit and airy. Respect any wishes that the client had about their final hours and make sure that all care givers are aware of their personal responsibilities. If the client's loved ones are unavailable but they didn't want to be alone make sure that care givers can provide constant company.

Chapter Five

After death care

Your responsibilities to your client do not end with their death; you have to take care of their body and respect the feelings of those who have been bereaved. Any requested religious rites will need to be carried out; required records and reports should be completed and the client's body must be appropriately prepared for collection. Anyone affected by the client's death should be given information, emotional support and time with the body if necessary.

Funeral management

Care planning should have identified if last rites or other religious observances are necessary and the appropriate priest, minister or other religious representative should have been contacted when it was decided that death was imminent.

Note: Always treat bodies with dignity and respect; act at all times as if you are being observed by the person's family and provide care in a way that is personally and culturally appropriate and meets any religious requirements.

Last offices cannot be carried out until the client's death is confirmed by a doctor or appropriately qualified nurse; they should be carried out by two care givers and the required skills can be passed from competent care givers to new staff

Before beginning ask relatives to leave the room unless they are going to be involved. Collect all necessary items and have them ready before you start so that you do not have to leave the room once you have begun. Medical equipment such as syringe drivers, catheters etc. must be removed by a doctor or nurse.

What you will require:

- Water
- Towels, flannels and soap
- A disposable razor
- Tools to clean mouth / dentures
- Incontinence pads
- Clean clothing as agreed with client or their family
- Disposable gloves and aprons
- Sheets
- Clinical waste bags
- Identification labels (if necessary)
- Valuables / property book

Steps should follow:

- Wash your hands and put on gloves and apron

- Lie the client flat and remove all but one pillow from under their head
- To prevent problems with rigor mortis place a pillow or rolled towel under the dead client's chin
- If necessary gently close the client's eyes
- Wash the client as appropriate and shave if required.
- Cover any open wounds to prevent spread of infection (if there is to be a post-mortem leave existing dressings in place)
- Clean mouth and dentures
- Remove jewellery as appropriate, record in valuables book and store safely
- Dress the client and put a clean incontinence pad in place
- If necessary put an identification tag on the client's ankle
- Change the sheets on the bed; cover the client with a sheet but don't cover their face
- Deal with laundry and clinical waste and wash your hands
- Check that everything is presentable before allowing people back into the room
- The bodies of clients who were suffering from notifiable diseases should be placed in waterproof body bags.

Documenting

When a client dies The Care Quality Commission must be informed.

In the event of an unexpected death the attending doctor must inform the police.

Unexpected does not necessarily mean unnatural but the police will need to look at where and how the client died and carry out an investigation. The coroner's office will be informed and a post-mortem will be arranged; the police will hand the body over to the Coroner's Officer and will complete appropriate paperwork.

Because post –mortems delay funeral arrangements it may cause distress when the client's beliefs require them to be buried or cremated as soon as possible after death. Families must be kept fully informed and care providers need to be honest and open about what is happening and why.

The following documents may be required for an inquest; they must be up to date and available

- Care plans
- Medical records
- Fluid charts
- Tissue viability sheets
- Daily logs

Bereavement Care

Family members, friends, other clients and care staff may all be affected by a client's death. Some will wish to view the body and may want to spend some time in a private room reflecting on the person's life and starting to come to terms with their death. You need to

recognise that people experience and express grief in different ways which will be affected by their culture, personality and religious beliefs.

You need to be prepared for any reaction including no reaction. Some people deal with negative emotions by closing themselves off and becoming incredibly business like but don't make the mistake of assuming that someone who shows no emotion isn't feeling any. It is not your business to judge people's reactions, treat everyone with equal tact and compassion.

If people are unsure about their official responsibilities following a loved one's death good guidance can be found on www.gov.uk.

Be available to provide cups of tea, a shoulder to cry on and sympathetic words and gestures of support if necessary. Try to maintain a calm and respectful atmosphere around the dead client's room.

Considering other clients

All clients should be encouraged to suggest ways in which they would like deaths to be dealt with; they may want to have some kind of celebration of life or to be supported to attend funerals. Be sensitive to the feelings of your clients and make sure that they have the opportunity to talk about deaths and to reminisce about the person who has died.

It has become a cliché to talk about 'closure' after a negative event but the purpose of a funeral or memorial service can be to mark an ending and start a healing process.

If client deaths are ignored how do you think that might affect clients who remain alive? Will they expect to be forgotten; will their care givers and friends act as if they never existed? Death is inevitable; your clients cannot be protected from it but they can be supported to enjoy their life and to have the best death possible

If you have difficulty dealing with the death of a client seek support and advice from your manager; it is not a sign of failure if you are strongly affected by death, it is a sign that you are human and that you care.

The following websites may be useful If you think that people might benefit from professional help and support:

www.crusebereavementcare.org.uk

www.samaritans.org

References

Common Core Competences and Principles for Health and Social care Workers Working with Adults at the End of Life

Published by NHS et al

End of Life Care Strategy

Published by Department of Health

Introductory Guide to End of Life Care in Care Homes

Published by The National Council of Palliative Care

Useful Contacts

www.gov.uk

www.endoflifecareforadults.nhs.uk

www.helpthehospices.org.uk

www.ncpc.org.uk

www.skillsforcare.org.uk

www.ageuk.org

www.alzheimers.org.uk