



**Wellbeing for Life
Talking about Death and
Dying**



Learning Outcomes

- To respect a person's wishes and beliefs to help them understand death and dying.
- To be able to apply the Mental Capacity Act on making decisions about death and dying.
- To understand the "ARCH" approach as a way of breaking and talking about bad news.
- To have ideas on how to start a conversation about death and dying.



Talking about Death and Dying

It's not a surprise to know that as a society talking about death is something that we tend to try to avoid thinking about and discussing. We may change the subject, talk about something else, take our minds off it or, even worse, we might try "sweep it under the carpet". We do this to protect our feelings. We do our best not to feel sad.

We see a person crying and it's a natural instinct to comfort the person and you may find yourself saying "don't cry, come on, cheer up". Time then goes by; it could be days or even months that you haven't revisited the conversation that you could have had weeks ago.

Then you may find yourself in a challenging position as you have "buried your head in the sand" and the conversations you should have had months ago are now unavoidable and maybe time is now limited.

Talking about Death and Dying

There is no right or wrong way to feel when you are faced with bad news but we want you to be as prepared as you can be. When you find yourself in circumstances like this you can dig deep and remember what you have learnt from this module; from training that you have taken part in or from your own personal experiences.

The chances are that people want to talk about death and the person who is dying wants to talk, let off steam, share their worries, plan their future and feel comfort from you.

This is never going to be an easy time but the importance of talking about death and dying will strongly help you in your role as a carer, family member or friend.





Tips for Having a Conversation about Death and Dying

- Be open to all conversations, listen to the person their views and understanding.
- Explore the topic of death and dying together – be respectful of their experiences and views.
- No one truly know what happens after death – explore what they think and do not force your view point onto the person.
- Respect that the person may not want to talk when you do.
- Be person centred and be as honest as possible.
- It doesn't matter if it's a long or short conversation; it's about what is discussed.
- Make sure you tell the person that what they say will be valued and listened to.
- Be honest and acknowledge that talking about these things can be hard.
- If it doesn't work the first time then try again another time.



Starting a Conversation...

- Take up all opportunities as they arise – watching TV, out walking, seeing a grave, a news item.
- Try leading questions – *if you become ill who would you want to sit with you? Have you thought about what you will do with your things when you die?*
- Provide obvious opportunities by leading the conversation to the future or about a relative who has died or ask them what they think about death.
- Sometimes raising the topic directly and honestly works.
- Use your personal experiences to start the conversation – *“I am writing my will...”*
- Provide reassurance and be honest about how you feel as well.
- Allow silences, don't be tempted to fill any gaps.



Keeping the Conversation Going...

- Keep the conversation going, don't be tempted to close the conversation down straight away.
- Don't fear tears – crying is a natural response to emotional situations. You will know how best to support the person with their emotions.
- Encourage the person to say more once the subject is broached.
- Be led by the person, encourage conversation but don't push beyond what the person is ready to talk about.
- Support the person to seek religious or spiritual information if that is their wish.
- Use easy read resources to support conversations.
- Keep the conversation equal – we are all dying, it affects all of us.

Remember: If you are worried by anything the person says or how they are coping with their emotions, discuss this with your Line Manager.



Talking about Life Limiting Conditions

- Nothing can prepare you to be told that you have a life-limiting condition. When a person is told, they will have many different thoughts and feelings, and each person may experience a different range of emotions; we are all different.
- You or the person may have expected this news, but having it formally diagnosed will still be a shock as it becomes real.
- The person may be in denial and not want to hear what has been told to them or not want to accept it.
- Being told that you have a life limiting condition may come as a huge shock, just by going to the GP for a check-up, can develop to tests being carried out and a hidden illness becomes apparent.
- If you support a person with a terminal condition (life-limiting) you need to prepare yourself that each person will have a unique attitude and your approach will be different for each person.



Talking about Life Limiting Conditions

- Having sensitive conversations and being mindful of privacy and who the person wants to know is vital; as is keeping communication open.
- You need to be aware that you may find yourself revisiting chats already had with the person; this can help the person deal with what's happening.
- You may have been with the person when they were given their diagnosis and knowing the person will give you insight into really knowing if they understood what was being told to them. If you think they didn't understand, you need to ask the Doctor to explain again. You may also need to spend time talking about what is happening in a simplified way over a period of time. Be creative in the way you do this to engage the person.
- You need to be aware of your feelings as this will be an emotional time. Don't be alone, talk to work colleagues and support each other.



Living Life to the Full

Talking about death should also lead to a discussion about life and what the person wants to achieve with their life.

Popular these days are a “Bucket List”. A bucket list is a great opportunity for a person to achieve all the things that they ever wanted and still want to do in their lifetime.

Anyone can write a list and you shouldn't wait till you are at the point of end of life. If you support a person at their end of life, a bucket list can be a positive thing to carry out. It will give a real focus for the person. This can provide a sense of purpose and a chance to take their mind off the everyday challenges that they may be facing.

Use the Person Centred Review Document, “Important To and Important For” to identify the person's hobbies and interests, their dreams and wishes. This can then lead to a bucket list of wishes and you can then help plan to achieve some, part or all of their dreams. What is important are the person's dreams, however big or small, and the support they need to work towards achieving their dreams.

For more information, please see our module on ‘Providing the Best Support’ in Theme 6 End of Life Care.



Involve the Person

Consider these points:

- Keep the person involved in decision making.
- Do they have an up to date Advance Care Plan in place? If not this needs to become a priority.
- They may require your support and you need to be there for them but encourage them to be involved in all decisions however small.
- If the person has a preference where they would like to die then support them in making this happen. If it is unrealistic then try and think of a realistic alternative for the person to consider – give them options to choose from.
- Be aware of the changes that the person is experiencing and ask them daily how they are managing their emotions, giving support as needed.
- Spend time with the person and reminisce over past events and memories. You may find yourself finding out new things that you didn't know about each other.
- Give opportunities for the person to take part in meaningful activities. A person may lose interest in current hobbies they once enjoyed so it's your role to introduce new ones but making sure that they are relevant to the person.



Involve the Person

Consider these points:

- Be aware of a person's cultural and religious beliefs and make sure these are listened to and respected, especially when a person cannot advocate this for themselves.
- Remember that their family and others will be affected too. Give information and listen to everyone. Signpost them to additional support and advice.
- Remember your own feelings, don't take on too much as you need to stay well and be realistic in what you can manage.
- Be aware that hearing remains, so when the person is in and out of consciousness they may still be listening to what's around them. Be aware of what you are discussing in their earshot, ensuring you maintain respect for the person.
- Discussing death doesn't bring it closer, it's about planning for life .Without planning and understanding death and terminal illnesses it can be a stressful and lonely experience both for the person who's dying and their friends and family



Being Open and Honest to Achieve 'A Good Death'

There are certain signs to look out for when a person is coming close to death. It is thought to be how a person's body prepares to die. If you are aware what to look out for, it can give you the chance to have last conversations and say your goodbyes.

Some of the signs you may notice in the last few weeks, days, or even hours are:

- Physical Changes
- An older person may develop paper like skin and paleness in their colouring
- Dark liver spots appear on the hands, face and feet
- Shrinks in stature or height
- Hair becomes thin
- Teeth can discolour
- Clothes not fitting due to changes in body shape
- Personality changes, feeling generally unwell
- Asking for more pain relief than usual



Being Open and Honest to Achieve 'A Good Death'

The Person may also:

- Stop wanting to go outside and be content in their bed; not wishing to connect with the outside world.
- You may find that the person does not wish to talk anymore and have changes in their mood or religious beliefs. You need to have an open mind about the person's wishes and embrace any change in their views.
- Start to sleep more, this can be upsetting for others but we must understand that any physical exertion for a person close to death will be exhausting for them. The person is putting all the effort they have into staying alive and this in itself will take much of their strength.
- Experience a change in appetite and it may stop altogether. Food and drink may not be what the person wants and you must be mindful not to force this upon them. If you are really concerned speak to the doctor and/or palliative care professional for advice.
- Start using new expressions to describe what they are feeling and want to say thanks to people in their lives. You should support them with this.



Advice on Communicating with the Person:

- Understand that the person's usual communication methods may no longer work for them and communication may need to be simplified or supported with communication aids.
- Touch can be very useful and comforting, and may also be how the person chooses to communicate with you for reassurance, kindness and compassion.
- Play the person's favourite music and sing to them, music can be very powerful at the end stages of life.
- Know that it is okay to be silent too; your presence is appreciated.
- If they are religious, could you organise for a religious leader to visit (eg vicar)? This might help the person receive appropriate religious acknowledgement in this phase of their life (such as blessings, last rites, etc).
- Talking to others whilst the person is still alive (eg peers, friends, housemates, staff, best friends etc) is really important; consider the impact on everyone.

For more information on this last point. We have a series of films on this on our website - <https://www.macintyrecharity.org/our-work/supporting-people-with-dementia/macintyre-dementia-project/registered-managers-perspective/5-impact-of-dementia-on-friends-flatmates-and-other-relationships/>

Talking with Others After a Person Dies



If you understand what happens after a person has died, you will be able to explain to people you support and others what is happening; reassure them and give as much information as they want and need.

After a person dies there are practical things that you need to carry out on behalf of the person.

Involve others as appropriate, it may help people to do something useful and give them an opportunity to talk to you as you both carry out practical tasks. It will be your decision on how much and when to involve people, at least consider involving them and even asking if they want to help you.



Talking with Others After a Person Dies

You will need to clearly explain where the person's body is. Use concrete language so no misunderstanding occurs. After a person dies their death is confirmed by a Doctor. If the person dies in hospital the body will lay in the hospital mortuary. If death at home was expected the body will go to the funeral directors; if the death was unexpected the body will be moved to the hospital or public mortuary. If the cause of death is unknown then the coroner will look into it and usually requires a post mortem to understand why the person died.

Support peers and friends to be involved in arranging the funeral, discuss with them the role they want to take and how they want to remember their friend or family member. Respect their wishes if they do not wish to attend a funeral, but make sure they understand what will happen at the funeral, that they will be supported and why people go to funerals. It is important to start with an assumption that peers and friends will attend the funeral. After discussions with the person or best interest decisions, it may be decided for them not to attend. Too often people with a learning disability are excluded from funerals because "they will be sad and upset". Funerals form part of a grieving ritual and have an important place in how we all cope with loss; people with a learning disability should not be excluded from this life experience.

For more information, please see our module on 'Continued Care and Support for Everyone After Death.'

Emotions that can be Experienced:

There will be many emotions and feelings experienced about death and dying. From the moment you find out a person is terminally ill, to the care you give, through to the final days and times after death.

You and the people you support may never feel any of the emotions listed here and there is no right or wrong way to feel. You need to remember that we are all different and each experience will be unique. It is good to share feelings and how to cope with the range of emotions. You will need to be sensitive to help people you support understand their emotions and what to do to help manage their emotions.





Emotions that can be Experienced:

Some of the feeling associated with death and dying:

Shock: you may have been prepared, but death can still be a shock, or the death might have been sudden

Fear: not knowing how you will feel, not having control of what's happening, of losing the person, of the person dying at home and how frightened that might makes their housemates feel

Anger: not wanting the person to die, being cross with the person

Resentment: having bad feelings towards others

Denial: not wanting to believe that the person is dying

Helplessness: feeling like everything that you are doing or saying just isn't helping, that you can't stop the inevitable

Sadness: the whole journey will create sadness. From the beginning to the end

Frustration: the feeling that you can't change things or take this away

Relief: that the person is no longer in pain and discomfort

Acceptance : coming to terms with what is happening and after a person has died



Using the ARCH approach to talking about “bad news”



Breaking and talking about bad news is a complex communication task that also involves a wide range of emotions.

The task of breaking or talking about bad news can be improved by understanding the ARCH Approach as a step by step model. In addition to following this approach all interactions must use the 10 Facilitation Skills that are MacIntyre’s Great Interactions TM



Using the ARCH approach to talking about “bad news”

The ARCH model is a person centred approach to breaking bad news. Breaking bad news is often difficult for the news giver and particularly for the person receiving the bad news. Using this approach is shown to help both the giver of bad news and the receiver of the news.

Be careful about making any assumptions about what is “bad news”.

“Bad news” can be any information which has as serious negative affect on the person’s view of their future – exactly what this is will vary from person to person.





Using the ARCH approach to talking about “bad news”

The Approach is called ARCH and the letters stand for:

- **Ask.** Find out what the person already knows. Always use the person’s name. Use straight forward questions to find out information. Ask what the person wants to know.
- **Repeat** and clarify. Be prepared to go over information time and time again, in different ways (using books, photo graphs etc) and simplify if necessary. Carefully listen to the person and be guided by what they want and need.
- **Check** level of their understanding. Explore how much they know about the illness or news and what it means to them. Go back to previous stages if necessary. Be guided by the person.
- **Help** the person to express feelings. Encourage expression of feelings, listen carefully and give support. Help the person to describe feelings, and explore what help they feel they might need, next future support options and choices and letting other people know if necessary.



Using the ARCH approach to talking about “bad news”



This model can help you talk to the person and really get an idea of what they understand, their values and wishes and how much they want to know.

The ARCH approach will help you think about how to break and talk about bad news.

You may find you need to deliver sad news to others after someone has died. By following the ARCH approach will help ensure they understand.



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