

## A Guide:

# How to talk about death and dying

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## **Introduction**

We should all feel empowered and confident to talk about death, ask questions, listen, and be sure of what we and our loved ones would like to happen when our time comes.

However, it is not always that easy to have a conversation about death and dying. It can be upsetting and uncomfortable for many of us – but it doesn't have to be that way.

Our aim is to offer support to people to approach and engage in those meaningful exchanges with friends and families, and to demystify the fear and anxiety around death.

This comprehensive guide on 'How to Talk About Death and Dying' offers reassurance, support and advice on having those important conversations with our loved ones.

We should also feel confident in asking the right questions, and challenging systems, organisations and health care professionals, about death and dying. It is all part of ensuring that our choices and wishes are at the forefront of our care and support when our time comes.

We believe that when we are able to face death openly, and approach it peacefully and positively as a natural part of life, we will feel empowered to live our days to the fullest. Talking about death and dying is the first step towards that reality, planning for life, and supporting ourselves and our loved ones.

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## **Why is death and dying so hard to talk about?**

Talking about death and dying can be one of the most difficult conversations to have – especially with our loved ones. It is okay to feel scared about approaching the topic, whether you are voicing your own thoughts and feelings about death or asking a loved one to open up about how they feel.

Usually, it is not until something ‘significant’ happens in our lives that we begin to ponder death and dying. It could be anything from having children, to receiving a medical diagnosis. It could simply be the realisation that we, or our family members, are getting older. It is at this point – when talking about death and dying becomes a reality that we have to face – that many of us find we feel anxious and unsure.

The hardest part of talking about death and dying is accepting our mortality: the fact that we, and our loved ones, will eventually face death. Naturally, it is a scary thought! Most of us have no idea what to expect and we don’t know when it will happen, either. A lot of the time, we’d prefer not to think about it, and ‘cross that bridge when we get to it’.

But the truth is, talking about death can help us to alleviate our fears and feel a bit more prepared. It does not, of course, bring death closer.

When we keep avoiding the topic, it perpetuates our ‘fear of the unknown’. However, by exploring all the different possibilities, and our thoughts and wishes, we are able to come to terms with the fact that it will happen one day, and start planning for how we want it to be.

Another worry that stops us from talking about death and dying is causing upset to ourselves and others. It is normal that talking about death and dying with our friends and family can uncover emotions that might be tough to deal with. Yet, showing emotion doesn’t have to be a bad thing. It is expected that no one wants to lose their loved ones, or leave their loved ones behind.

We avoid conversations about death and dying because we feel frightened of what we may hear, and anxious that we may not be able to handle a conversation emotionally. We worry that we won’t be able to put things back together again if we create emotional upheaval.

Even having conversations about Wills can bring about worries of being ‘money-grabbing,’ so we avoid the topic. We shut down conversations and say, ‘don’t talk like that, you’ll be around for years yet’.

Perhaps we have never been a talker, and we don’t want to start now!

Sound familiar? Don’t worry; all of these feelings are completely normal, and most of us experience them. The best thing we can do is try to work through them, so that we can talk about these important things with our loved ones.

## **Why talking about death is so important**

Despite the fact we don't like to talk about death and dying, most of us have a quiet wish that we will die peacefully and with dignity, without any pain. We hope that everything will be okay after we are gone, and that our families will be able to cope without us.

When we plan for death, we are able to voice this quiet wish and help to make it a reality. We are able to decide what kind of arrangements we would like to have made for us. We can rest assured that our wishes will be followed, and that our families will be looked after throughout the entire process.

Taking consideration of the practicalities of dying – such as our physical and psychological care, our Will, our funeral, our housing, finances, pets, and more – can lift a huge weight from our shoulders, and minimise the stress our families may be left to deal with at what will already be a distressing time.

Additionally, when we are open to talk about death and dying with our loved ones, we create an opportunity to engage in meaningful exchanges before it is too late. We can feel empowered to say things like, 'I love you,' or 'I'm sorry,' or 'I'm proud of you'.

Facing death can reveal many different emotions that are difficult to deal with. All of the following things are completely normal:

- We are frightened of dying
- We feel we are a burden to their friends, family or society
- We are angry to be 'cheated of life'
- We feel lost and alone, and desperate for someone to ask how we feel
- We feel angry and let down by our God
- We are clinging onto hope for a miracle cure
- We are grieving for missed opportunities and feeling as if we have wasted our life
- We are desperate to die
- We want to make contact with estranged family or friends
- We want to confess to things that have happened in the past, or to ask for forgiveness
- We may become irrationally angry, blaming and resentful towards others, or the medical and nursing staff, or the world in general
- We are missing relatives and friends who are unable to be with us

Thankfully, there are organisations across the UK that are able to offer professional support for all of these worries and needs. For example, hospices can offer vital care and support to local people, free of charge.

Hospices can offer care to keep us comfortable at the end of our lives, but also support us through physiotherapy and occupational therapy, to empower us to live our life in the way we want, however long we have.

They offer practical, psychological, emotional and spiritual support through counsellors, social workers and chaplains – which extends to family members, as well. Many hospices also offer complementary therapies, such as massage, reflexology, reiki, aromatherapy, beauty/grooming treatments, and more.

Our lives matter to us; our stories matter to us. It can, therefore, be said that the endings of our stories matter, too. In our lives, we have the ability to take steps to make the ending of our story that bit easier for ourselves and our loved ones. Death need not be perceived as a ‘failure’; although it is always sad, it can be a ‘happy-ending’.

## **What happens if you don't talk?**

Talking about death is a scary thing. All of us can relate to that! We've all felt upset, uncomfortable or awkward when the topic is approached, which leads us to avoid it in the future. Although our intentions are usually good, and we don't want to cause any upset, in the long-run the consequences can be difficult to deal with.

Often, people who have experienced the death of loved one express that they wish they had been more prepared. This might be in terms of arranging practicalities or in having meaningful exchanges with their loved ones. Sometimes, people are left unsure of what their loved one would have wished for, or important things were left unsaid.

People have also expressed that they wish they had learned more from the healthcare professionals involved in caring for and supporting the family. It might be what to expect physically when someone dies, or advice on how to navigate the healthcare system. Remember that it is always okay to ask questions, whatever they are.

Talking about death before it is too late relieves us of unnecessary complexity at what is already a very distressing time. It can help everyone in the family to feel supported and able to accept what will happen.

Here are some examples of the things that we can avoid by simply talking about it and making arrangements in advance:

- Having to be referred to the court of protection because power of attorney couldn't be authorised
- Stressful administration of finances after someone has died with no Will
- Not being told that a loved one is dying, so missing opportunities to say goodbye
- Missing the chance to ask someone's funeral wishes and being left unsure of how they would like to be remembered
- Not knowing whether your loved one would have preferred a cremation or burial
- Important things are left unsaid within families

## What we might want to say

Opening conversations about death and dying can begin to ensure that our wishes are followed when the time comes. We should all feel empowered to talk about it with our friends and family, as well as healthcare professionals who take care of us.

First of all, talking about death creates an opportunity to think about some practicalities, so that they can be discussed and settled. This can relieve us of some of our fears and worries. We might be feeling anxious about certain practicalities that we must face. Talking about it can shed light on what we can expect, and help us to feel reassured that our wishes will be followed. Here is a list of practicalities that you might want to discuss:

- Making a Will
- Planning the funeral
- Arranging care and support
- Our preferred diet and nutritional needs
- Personal hygiene and going to the toilet
- Life-support machines
- Who will make decisions for us
- Organ donation
- Cremation and burial

Very importantly, creating opportunities to talk about death and dying can encourage us to say things that we may have difficulty expressing to our loved ones. These are things that are important to us, but we fear what might happen after we say it. We all have inner thoughts like these, which we wish we could say:

- I love you
- I'm sorry
- I'm proud of you
- Thank you
- I miss you
- I forgive you
- I trust you
- I'm frightened

We all have an emotional need to feel heard, connected and safe, and we all want to be understood and accepted. Expressing our true emotions can encourage feelings of peace and acceptance.

We understand that talking about death is a bit of a taboo. Yet, when we talk about it, we actively help to break down those barriers, and make it that bit easier and acceptable for people – especially children and the next generation.

Death does not need to be perceived as a scary thing at the end of our lives. By talking about it, eventually it may be accepted as inevitable part of life that can be approached as peacefully and as positively as possible.

## How to start a conversation

If you are reading this: well done! Taking that first step to talk about death and dying is not easy for anyone.

There are many reasons that you might want to start a conversation. It could be a personal need to explore your thoughts and emotions, family issues or misunderstandings that have arisen, or to comfort a loved one. It could be that you or a loved one has received a terminal diagnosis, or that someone else you know has died. It could simply be that you are looking to prepare for when the time comes in the future.

Whether you are starting a conversation about your own thoughts and feelings about death, or asking a loved one to open up, approaching the topic sensitively is always a good place to start. Trust in your own judgement, and treat the person you are chatting with as you normally would. You will intuitively know what would be the best way to start talking about it.

If you're not sure on how to approach the subject, then you are not alone! Here are some ideas on how you might start a conversation about death and dying...

### 1. Recognise opportunities

Sometimes, the conversation will come about unexpectedly. You could be out for a walk, having dinner, or enjoying a drink together.

Listen for natural openings to bring up death and dying. Perhaps you are discussing a recent tragedy in the news: "I wonder what the families are going through right now?" You might bring it up by talking about the death of someone famous, and how it has impacted you.

Often, conversation-starters like this can lead on to having more meaningful exchanges as the discussion develops.

### 2. Ask questions about death

Another way to start a conversation about death and dying is to ask questions about people's experiences. If you feel comfortable and are confident that it would not cause upset, you might ask an older relative, "What was it like when your parents died?"

Often, people will have stories and memories about their loved ones, and will be happy to share them with you. Listen well, and remember what they tell you about what was important, what they cherished, and if they had any regrets.

You then have the opportunity to sensitively ask, "What would you like to be different when it is your time to die?"



### **3. Talk about your own experiences**

One of the best ways to open a conversation about death and dying is to talk about your own experiences. Mentioning what happened or how you felt can encourage others to open up about their own feelings and emotions.

Take care to be real and honest with people. You should also think about how you can reassure that your experience was normal and natural.

You could also talk about recent books or films that you have seen that address the topic of death and dying.

### **4. Be thoughtful and considerate**

You may need to guide a conversation to happen, arranging a suitable place and time and planning what you want to say. Think about what you wish to achieve, so that you can manage any apprehension and stress you may feel, and have the confidence to keep the conversation going – even if the other person tries to close it down.

At the same time, you should be respectful that a person may not want to talk. It is important that you have the conversation about death and dying at a time when you and that person feels ready to do so.

### **5. When you don't have much time**

Sometimes, we feel a need to talk about death and dying because the situation has become critical. You, or a loved one, may not have long left to live. Take comfort in the fact that even in the most critical of times, there is always time to thoughtfully consider what the best thing to do is.

Although we may not have time to take care of any practicalities, there is always time to share how we feel and what we think. It could be a few words, or just a knowing look. Also, even if someone who is dying appears unresponsive, it is likely that they will still be able to hear you.

## Having a conversation

There is no right or wrong way to have a conversation about death and dying. It is different for all of us. There are so many things that we might want to talk about, including practicalities, and our thoughts and feelings, but it is up to us how we communicate them.

Often, we search for the right or clever thing to say in difficult situations such as these. Sometimes, we make light of it and try to make a joke. This is normal – even humour has an important place in death!

You will know what tone and language to use around your loved ones – follow your instinct. There is no need to treat someone differently to how you normally would. When you engage in a meaningful conversation, it is important that it feels real and familiar.

Remember: it is okay when you don't know what to say. There will very likely be instances when you are lost for words. As long as you have listened well and are showing consideration and compassion, it will be appreciated that you have shown your care. Above all, it is important to just be there.

Here are some tips that might help to you in your conversations:

### 1. Be respectful

None of us truly know what is going to happen after death, whatever our religious or spiritual beliefs. So it's important not to force our viewpoint onto the person. This is their experience.

### 2. Be honest

Being real and honest with a person can be very liberating and soothing – both for us and the person we are talking to. Although we might want to make a joke, or try to say something witty, sometimes the best thing we can do is hold a hand and be there.

### 3. Use body language

Don't be afraid to look your loved one in the eye; it is a key way of showing that you are listening. Be mindful and attentive of the way you and they are saying things, too. Things like tone of voice, body language, facial expressions, willingness to engage and give eye contact, are all part of the conversation. Are you saying what you really mean – are they? Say what you really mean, and invite them to do the same.

### 4. Stay calm

Talking about death and dying can understandably bring about feelings and emotions that are difficult to deal with. You might feel embarrassed by the emotional

intimacy of a conversation, or fearful of seeing your loved one appear vulnerable. You may feel angry that they are desperate to die, or even relieved, guilty or helpless.

Just breathe slowly to calm yourself, with both feet firmly on the floor. This will help to accept what is happening and be present.

## **5. Ask questions**

Try indirect questions such as:

- I wonder if there's anything you want to talk about?
- Perhaps you want to tell me about something bothering you?
- How can I help?

This empowers your loved one with the choice to respond, or to say no. As long as the door is open to talk or ask for help, you have shown that you care and are there for them.

Try leading questions such as:

- If you become really ill, would you like me to sit with you?
- When I am unable to respond to you, could you play me my favourite music?
- If I become very unwell, can you try to make sure that I die at home?
- Have you ever thought about what you want to do with your belongings?
- When I'm gone, can you make sure someone looks after my dog?
- Have you thought about what kind of service you would like at your funeral?

Again, this offers your loved one the choice to respond, and may make it easier to think about some of the answers.

## **6. Use short statements**

Short statements that show you care can also provide comfort.

- If there ever comes a time when you want to talk about something or you feel frightened, please do tell me.
- I am always here for you when you need me.
- Although I won't live forever, I will always love you and be proud of you.

Encourage your loved one to talk to you at their own pace, and at a time when they are ready. By saying little things that offer reassurance and show that you are a safe person to talk to, they may feel more inclined to open up.

## **7. Don't fear tears or emotion**

Whilst you should try to remain calm, it is also perfectly okay to express your emotions and be honest about how you feel. Talking about death and dying can bring about a range of emotions, which can be confusing. This is normal!

Don't fear tears; it's okay to cry. Crying is a natural response to emotional situations, and helps us to relieve stress. Being brave enough to let yourself express strong emotions can have a powerful healing effect on you, the person you are talking to, and your relationship. It also gives others permission to show their emotions.

#### **8. Be quiet**

Don't feel you have to talk all the time, and fill every silence. Just being there quietly, and showing someone that you care, can be surprisingly peaceful. It also gives you and the other person an opportunity to think, and say what you want to say.

## Talking to clinical professionals

If you or a loved one is unwell, you may also want to talk to a healthcare professional about death and dying. This could be your GP, a nurse, a healthcare assistant, a doctor, a counsellor or social worker, a chaplain... Whoever is taking care of you or a loved one will be able to answer your questions, and there is plenty of support online that you can find.

Here are some examples of the type of thing you might like to say and ask:

- What is it like to be there when someone dies?
- What can I expect at a funeral?
- What is a dead body really like?
- Will it hurt when I die?
- Can they see or hear me when they are dying?
- I feel like I can't cope now they have gone – can I access support?
- Who will care for me at home now I am alone?
- What are my options in terms of care?
- Can I die at home if I want to?
- I need someone to come and sit with me at night time.
- What is the first thing I should do when they die?
- I am scared about my treatment.

Try to be calm and confident so that you can think about what you need to ask, and remember what the answers are. You can take a notepad to make notes if you need to – this way you can repeat the information to your loved ones if you want to.

If you do not have access to the internet, many organisations and charities have 24 hour advice lines that you can call to access immediate support and advice. The number for St Clare Hospice's 24 hour advice line is: 01279 773773.

## Talking to children about death and dying

Sometimes, adults hesitate to bring children into conversations about death and dying. We think we are protecting them when, in fact, we cannot protect our children from death. They encounter it all the time – whether it be a dead bug in the garden or a mouse the cat brought in; or something very personal like the fact that their grandparent is going to die soon.

Although our good intentions are there to protect our children, they can unfortunately lead to feelings of exclusion. Children may feel unable to ask questions about death and dying if we do not include them in conversations. Naturally, their imaginations run wild, whilst the truth may be less scary!

Leaving children alone with fears and misunderstandings can cause them to grow and worsen, which can lead to feelings of isolation or guilt about what they think.

It is a lot better to support and help children to understand death, and things like funerals, before they are confronted with them when a loved one dies.

We should encourage our children to express their emotions, and include them as a member of the family.

We can begin talking about death with children by...

- Talking about how life and death go together in the circle of life
- Using examples in the natural world, such as leaves falling or flowers withering, we are able to express that death is a normal part of life that every living thing encounters.
- We can also use books to talk about death and dying – there are many books that have been specifically created to help teach and educate children
- Finding a dead animal or insect, or when a family pet dies, can create an opportunity to start talking about death. Let the child be there when the animal is buried, and carry out rituals like sharing memories, reading a poem or planting flowers
- We should let children come to funerals if they want to, because they are a way of saying goodbye. It is a good idea to tell them what they can expect beforehand. For example, the dead person is carried down the aisle in a coffin, people may be crying and upset, a curtain may close around the coffin, people will read things like poems, afterwards there will be a party where people eat and drink in celebration of their life...

Sometimes, children are able to talk about death a lot more easily than adults! They may ask questions that sound strange, but their thoughts and feelings are all perfectly valid and sensible.

For example, children may ask things like:

- What's it like inside a coffin?
- What does a dead body look like?
- Do dead people turn into ghosts?
- What's it like in heaven?
- What happens to the body when it gets buried?
- Does cremation hurt?

You can reassure a child and help them to understand their thoughts and feelings by talking through these things. Even if you don't have the answers or don't know what to say, a child will appreciate that you have tried more than if you dismiss or ignore them.

Here are some tips:

- Listen carefully and try to understand what the child means
- If you don't know the answer, say so. It's okay!
- Try to be direct and say 'died' and 'dead' instead of 'passed away,' 'lost' or 'gone to sleep' to avoid confusion
- Show that talking about death and dying is allowed
- Show your emotions; it's okay to be sad. It can help a child to feel their grief is acceptable, too
- Ask questions like, 'What do you think?'
- Be honest

There are some difficult questions that you may have to answer, but there is no need to be nervous or worried about it.

Q "Am I going to die?"

A "Everyone dies eventually, but it probably won't be for a long time."

Q "Are you going to die?"

A "Most people die when they are old."

Q "What does dead mean?"

A "Something or somebody that's dead doesn't move, or eat, or breathe, or do anything. They cannot feel pain, and will never wake up."

The best thing that we can do for children is support them to explore and express their thoughts and feelings in a safe environment. Make time to take their questions and curiosities seriously, and help to demystify death and dying for future generations.

## If you're a professional

Some of us have roles that mean we encounter conversations about death and dying more than others, sometimes within our jobs and at work. Here are some examples of the type of role that might support people through death and dying:

- Healthcare staff
- Support staff in healthcare settings
- Mental wellbeing support
- Funeral directors
- Businesses that offer funeral planning
- Insurance brokers
- Leading figures in different community groups

It is our duty to provide any relevant information a person may request, and provide a listening ear for people to express their thoughts and emotions. Although we may be busy, there is always time to show compassion and human respect to those who we work with.

- Don't leave people to flounder and 'scratch around' for information. Provide reliable information or show people where they can find out more
- Don't let your own fears of talking about dying get in the way of conversations. Be confident and compassionate, showing that you are a reliable and safe person to talk to
- Don't leave the person who is dying or the family to broach the subject. Give them the opportunity to talk by broaching it gently and showing that you are there
- Don't be vague or use language that a person may not be able to understand – such as jargon. It is key that you are a trusted professional who is able to provide support and reassurance

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This informational guide was created in celebration of **Dying Matters Awareness Week 2018**.

**Dying Matters** is a UK charity, led by the **National Council for Palliative Care**. Every year, they hold an Awareness Week that aims to bring death and dying to the forefront of conversations across the nation.

The campaign for 2018 addressed the question, 'what can you do?' encouraging the public to talk more openly about death, dying and bereavement, and supporting people in making plans and preparing for the end of life.