

Talking about death and dying

Adapted from: <https://www.dyingmatters.org/page/TalkingAboutDeathDying>

What to say, how to say it and where to find help.

It's not always easy to know how to talk about dying. Awkwardness, embarrassment and fear means we tend to shy away from connecting with those who are dying or those who are grieving. But when we don't talk about what matters it can increase feelings of isolation, loneliness and distress. In this section you will find practical guidance, information and resources on: how to say goodbye; the importance of good listening skills; and what the dying may experience as death approaches. There is also guidance on ways to offer spiritual support.

Fear of talking

It's not only relatives and friends who might find it difficult to talk about what's happening. The dying themselves often find it very hard to express what they are feeling or what they would like.

Why relatives and friends won't talk about it

Reasons may include:

- Fear of saying the wrong thing and making matters worse
- Fear of loss
- Cure collusion (refusing to face the truth, or pretending everything's alright) with relatives, doctors and caregivers
- Fear of what other relatives might say
- The notion that professionals know best, so nothing is addressed
- Fear of own mortality
- Guilt/shame about what has happened in the past
- Denial - I can't face the truth of what's happening

Why people who are dying won't talk about it

The ability or willingness of someone who is dying to talk openly about what they're going through may be affected by some or all of the following:

- Fear of being burden to family and friends
- Lack of privacy, particularly in hospital wards
- Inner conflict and unfinished business
- Fractured, strife-ridden families
- Secrets that have never been shared
- Denial – I don't want to face the truth
- Fear of upsetting relatives
- Never been a talker, and don't want to start now
- Trusting the right person (a dying person may choose who they want to talk to, and this might not be a relative, trained nurse or doctor).

The most important thing is not to push anyone into talking if they don't want to. Just make sure they know you are willing to listen if and when the time is right.

Starting the conversation

The following guidelines are aimed at relatives, friends and caregivers. But they may also be of help to anyone who is facing the end of life and doesn't know how to reach out.

Saying goodbye

Of course, dying people need appropriate physical pain control. But they also have what might be termed 'soul needs' – to feel heard, cared-for, connected and emotionally safe. Dying people want to be understood and accepted like anyone else.

Some people are fortunate in being able to approach their dying process at peace with themselves and with those they love. But that's not always the case. People can be frightened, confused, unable to express what they're feeling or what they need.

- They may be afraid to die.
- They may feel they're a burden to their friends, family or society.
- They may be raging at the thought of being cheated of life.
- They may feel lost and alone, and desperate for someone to ask how they truly feel.
- They may feel angry and let down by their God.
- They may be clinging onto hope for a miracle cure.
- They may feel as if they have wasted their life and are grieving missed opportunities.
- They may be desperate to die.
- They may want to make contact with ex-partners or estranged family or friends.
- They may want to confess to things that have happened in the past, or to ask for forgiveness. This can be painful and upsetting for relatives, but it can also be powerfully healing.
- They may also become irrationally angry, blaming and resentful towards you, or the medical and nursing staff, or the world at large.
- They may be missing relatives and friends who are unable to be with them.

If your relative or friend is becoming anxious or upset and you feel unable to deal with it, do talk to the nursing staff. The person may not be able to tell you exactly what's going on for them. Indeed, they may find it difficult to understand themselves. But they may be willing to talk to a nurse, pastoral counsellor, volunteer visitor, or particular friend.

Do your best to be there for the person who is dying, in any way that you can, but make sure you take care of yourself too. You may feel okay about being alone with the dying person. You may want and need company. But be aware that some close family members may find the thought of sitting with their dying relative too upsetting.

Saying goodbye in person is an important process for everyone. With gentle encouragement and support, anxious or frightened relatives can often overcome their alarm and find comfort in having done so.

How to open up difficult conversations

People who are dying usually know what is happening to them. Nevertheless, when a dying person believes relatives and friends can't cope with the truth, it can be hard for them to talk about what they're experiencing or ask for what they want or need. This can leave them feeling isolated and lonely, not knowing how to reach out or say goodbye.

So, how can a meaningful conversation happen?

A dying person might sometimes help indirectly by throwing out 'tester questions' to check if you are willing to engage with them. They might, for example, ask you, 'What do you think happens to you after you die?' They might ask if you think there is life after death. They might ask, 'Do you think God really exists?'

On the other hand, you yourself may want to broach the subject of death with your relative or friend, but don't quite know how, especially if death has never been mentioned before. One of the easiest ways of opening up the subject is to ask your relative or friend who they would like you to contact if they became very seriously ill. This conveys that you know they may not recover and are willing to talk about it. It also gives them the space to decide whether or not to respond.

If you don't feel quite ready to have this kind of conversation and you're in a hospital, hospice or care home setting, talk with the nursing staff so they can offer appropriate support.

How to listen well

The most important gift you can give to a dying person is to listen. Here are a few golden rules of good listening which can help you open up communication:

- Be respectful: none of us truly knows 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.
- Be honest: often in difficult situations we tend to search for the 'right' or clever thing to say. Or we deny what's happening, or make a joke of it. While such reactions are very understandable – humour has an important place too, even in death – dying is a profound process that just needs us to be there, and perhaps hold a hand. The act of sharing ourselves openly and honestly can be very liberating and soothing for the dying person.
- Use engaged body language: don't be afraid to look your relative or friend in the eye. Be alert and attentive to what they are telling you, and the way they are saying it. Listen to their tone of voice and be aware of changes to their facial colour; their willingness to engage with you; their willingness to meet your eyes.
- Watch their body language: is what they are saying really what they mean? Are they asking you something with their body language that they are not expressing with words? If so, invite them to tell you what they really want to say.
- Stay calm: you may also feel embarrassed by this kind of emotional intimacy, or fearful of seeing your relative or friend cry or become helpless and vulnerable. Breathe slowly to calm yourself.

- Keep grounded: ground yourself by physically feeling your feet firmly on the floor. This will help you to be present and accepting of what is happening.
- Try indirect questions, such as 'I wonder whether there's anything you want to talk to me about?' or 'Perhaps there's something bothering you which you want to tell me about?' or 'What can I do to help you at the moment?' This gives your relative or friend the choice to respond, or to say no. Providing choice is empowering. They may decline initially, but will know the door is open if they want to talk about it later. Indirect, exploring questions give the signal that you are safe to talk to, and that you care.
- Try leading questions: you can also gently ask leading questions to find out how they are feeling, such as, 'If you become really ill, would you like me to sit with you?' or 'If you become ill, what medical care would you like?' or 'Have you ever thought about what you want to do with your belongings?' or 'Have you thought about what kind of service you would like at your funeral?' Again, this provides the dying person with the choice to respond or not.
- Use short statements: these can also provide comfort. You might say, 'If there ever comes a time when you want to talk about something or you feel frightened, please do tell me'. This gives your relative or friend permission to talk in his or her own time, without expectation.
- Don't fear tears: it's okay to cry; crying is a natural response to emotionally charged situations. Being brave enough to express your grief can have a powerful healing effect on your relationship, as well as giving your relative or friend permission to grieve for the life he or she is leaving behind.
- Be quiet! Don't feel you have to talk all the time. Just being there quietly at the bedside is important, and can often be surprisingly peaceful.

Spiritual support

Spiritual care at the end of life is now recognized as part of good palliative care. Many people die without a religious or spiritual belief and this must be respected. But research shows that the nearer we come to the end of life, the more questions can arise about the meaning and purpose of our existence.

Don't be afraid to knock on the hospital chaplain's door. They are there to provide help and support whether it's for your dying relative, or you need to talk about things that are distressing you. You can also ask for pastoral support to be organized for the dying person by hospice and care-home staff. Chaplains will arrange for prayers to be said, and last rites to be administered if the dying person is a Christian. They will also arrange for other faith ministers, priests or rabbis to visit or talk with the dying person.