

When someone you care about is dying in hospital

- What to expect -



Seirbhís Sláinte
Níos Fearr
á Forbairt

Building a
Better Health
Service

Foreword

If someone you care about is dying, this booklet may help you to know what to expect in the last days and hours of their life. We understand this is an emotional and challenging time for you. We hope this booklet will help to make this time a little easier.

Talk to the healthcare team in the hospital if there is anything worrying you or the person you care about. The healthcare team is made up of doctors, nurses and support staff.

This booklet is freely available for anyone who wants to read it. Please take a copy for yourself or give it to anyone who you think will find it useful.

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**HospiceFriendly
HOSPITALS**



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Putting Hospice Principles into Hospital Practice

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1. Introduction

When someone you care about is dying it can be hard to know what to say or do. Sometimes it is hard to know how to comfort the person who is dying.

This booklet aims to help you to understand what is happening when you are in this difficult situation. Some deaths are sudden, and not every death in hospital is expected, so some parts may not apply to you.

This booklet includes information about:

- some of the changes that can happen when someone is dying, and what you can do to help
- talking about feelings
- talking about beliefs
- what to do if someone dies while you are with them
- looking after yourself
- talking with children about death and dying.

The person who is dying may already have told you and/or the healthcare team about what they want for themselves at this time. The healthcare team will do their best to follow the person's wishes, respecting their right to confidentiality.

Every person is unique, so every death is different.

This booklet deals with the most common concerns and questions. You can ask the healthcare team if you have any other questions or concerns. They are there to help you.



2. Coping with changes in the person who is dying

This section explains some of the changes that are common when a person is close to death. When a person enters the final stages, dying may affect their body or mind, or both.

These changes are a normal part of the dying process. Sometimes these changes appear a few days before death, sometimes a few hours. These are part of the normal, natural process of the person's body slowing down. This is an uncertain time and difficult to predict.

If any changes worry you, please speak with a member of the healthcare team.

Changes that may happen include:

- not wanting to eat or drink
- becoming restless
- getting cold hands and feet
- sleeping more
- becoming confused
- changes in breathing
- having pain or discomfort.

These changes do not happen in a set order. Not all of them happen to everyone.

Not wanting to eat or drink

When close to dying, many people stop wanting to eat or drink, their lips and throat can sometimes get dry. This is normal, but it can be upsetting for those who care about them.

You can help them by gently wetting their mouth and lips with a mouth sponge. Applying a lip balm can also help. This will usually be enough to keep the person comfortable.



The healthcare team can explain what is going on, what to expect and what they are doing to provide care and comfort at this time.

Becoming restless

Sometimes the person who is dying can become restless. They may be anxious, or make repeated movements, such as pulling at their blankets or clothes. This is usually because of physical changes in the body.

Getting cold hands and feet

The person's hands and feet may feel cold, and may change colour. This is because their heart is sending blood to the vital parts of the body, and it is not reaching their arms and legs. You can put extra blankets over the person's hands and feet to keep them warm and comfortable.

Sleeping more

As a person is dying they may spend more time sleeping. When they are awake they may be tired and sleepy, with little energy. They may not want to speak. They may slip in and out of consciousness. This is normal.

Let the person relax and rest. It is important to remember that hearing does not always fade before death, so even when the person seems less conscious they may be able to hear you.

You can let them know that you are with them by speaking, holding their hand or doing something that you know will comfort them. Speak softly and clearly, and use the person's name. Talk to the healthcare team if the person's restless actions are upsetting them or you.



Becoming confused

When awake the person may be confused about where they are, the time of day, who you are or even who they are. They may see or hear things which are not there. They may appear to speak with people who have died before them.

You can remind the person gently about reality, and reassure them they are safe.

Let them know you are with them by speaking, holding their hand or doing something that you know will comfort them. Speak softly and clearly, using the person's name. Talk to the healthcare team if the person's confusion is upsetting them or you.

Changes in breathing

As a person nears death, their breathing will change. It may get very fast, or become slow or shallow. The person may appear to be breathless. When they are very near to death, there may be long gaps in a person's breathing. You can continue to hold their hand and speak to them in a reassuring way.

You may notice loud or soft gurgling noises coming from the person's chest. The noisy breathing will usually not disturb him or her, although it may be upsetting for you to listen to. This type of breathing does not mean the person is in pain. Talk to the healthcare team if you are worried about the person's breathing.

Having pain or discomfort

You may worry that the person you care about is in pain or uncomfortable. However, in most circumstances she or he will have little or no pain. The healthcare team will do all they can to make sure the person is comfortable, for example, by changing their position in the bed if needed.

You can tell the healthcare team if his/her pain or other physical symptoms seem to get worse. The team will give medication as needed to ease the symptoms so that the person who is dying has as little pain as possible. The team may also ask the opinion of specialist palliative care staff. The healthcare team will answer any questions you may have about symptoms or medications.



The healthcare team can explain what is going on, what to expect and what they are doing to provide care and comfort at this time.

3. Talking about feelings

The time approaching death can be an emotional time for everyone. The person who is dying, and people who care about them, like you, may go through a range of emotions. These may include shock, anger, upset, fear, denial, helplessness, relief, frustration and acceptance. These feelings can come and go in any order. Both you and the person you care about may go through all of them, or some of them, or none of them.

People respond in different ways. There is no right or wrong way to deal with these feelings.

This part of the booklet aims to give you some ideas about what you can do or say to support the person when they are going through these emotions.

This section outlines:

- what you can do to support the person who is dying
- talking about dying and death
- talking to children about dying and death
- touch
- being quiet together
- letting go.

What you can do to support the person who is dying

Sitting with the person and listening is very important at this time. Careful listening helps the person who is dying to share their feelings. It may also help you to understand their concerns.

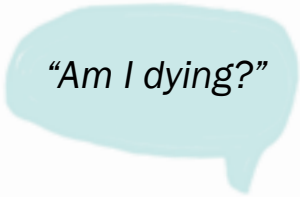
Be respectful of what the person says. Try not to brush them off or change the topic. Most people just want to be listened to as they express their hopes and fears, they may just want to know that they are not alone.



Talking about dying and death

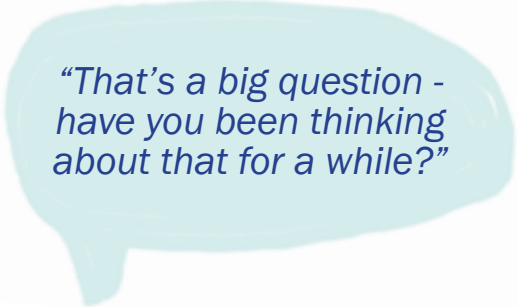
Talking about dying and death can be very difficult. Many people find it hard to know what to say. People can react in ways you might not expect. Some people avoid talking about it. Some remain positive, while others want to talk more openly. You may not be sure of what to say at this time. There is no right or wrong way to deal with this. Everyone is different. It is helpful to let the dying person talk about what is on their mind.

Let them take the lead in the conversation. They may talk about dying in an indirect way, such as by asking, “Is there life after death?” On the other hand, they may be more direct and ask:



“Am I dying?”

If you can, it is good to respond to any questions. If you feel stuck for words you could say something like, “Are you worrying about something?”



*“That’s a big question -
have you been thinking
about that for a while?”*

Although it can be hard, it can be good to talk about the truth if that is what the person wants. Some people who are dying do not want to focus on what lies ahead or to talk directly about the end of life. But at the same time they may want to be reassured about what is happening and that they are getting the right care and support.

When you are talking about death, it helps to listen carefully and to let the person speak freely. This may be about practical, emotional or spiritual matters.

Some people don't feel ready to have this kind of conversation. The healthcare team are there for support.



It is important that you look after yourself at this time. For more about this, see page 22. Talk to the healthcare team if anything is worrying you.

Talking to children about dying and death

Children who are close to the person who is dying may have many questions. How much you tell them will depend on how old they are. Very young children do not always understand illness and older children may want to know more.

Even very young children can tell when something is wrong, so try to be as open and honest as possible, using words they will understand. The social work staff or other members of the healthcare team can help you to deal with children's questions.

Touch

You do not always have to use words in order to communicate. Indeed, you may find it hard to find words for what you want to say to the person who is dying. At times like this, touch is a good way to let the person know you are there. This simple act can be very important and valuable. It may also be comforting for both of you.

You could hold the person's hand or gently stroke or massage it. Many people find this reassuring. It can also help the person to relax, sleep or deal with discomfort. Sensing you are there can bring great comfort and peace.



Being quiet together

As the person becomes weaker, they will have less energy for talking. Sometimes they may not want to talk. That is fine. Just knowing you are always ready to listen to them can be very reassuring. It can be good to keep your friend or relative company as you sit in silence together.



Letting go

Saying a final goodbye is never easy and some people find letting go difficult. Tears and talking about memories can be part of saying goodbye and help you both let go. Some people want to be there every moment. Others find it difficult to spend time with their loved one when death is near, some people don't get to say goodbye and some people don't cry.

Everyone is different and unique.

The pastoral care team and other healthcare staff can give you support at this time.

4. Talking about beliefs

When they are seriously ill or dying, many people think about the meaning and purpose of life. They may say things like, “Why is this happening to me?” or “What has it all been about?” These are deep and personal questions. Many people get consolation just from saying them.

Some people who are seriously ill or dying ask themselves questions about life and death. Sometimes it helps to think or talk things through with another person. Some may want to talk about spiritual or religious matters with a religious leader or a spiritual person. People who do not have any religious or spiritual beliefs may also want to speak about what is happening.

Many people find it consoling to think and talk about these things. Indeed, you may find the experience of being with the dying person is meaningful and spiritual for you, too. Your dying relative or friend may want to pray, meditate or reflect with you.

Most hospitals have a chaplain or pastoral care staff who can help people with spiritual matters. Pastoral care is there for everyone, whether they have religious beliefs or not. The pastoral care team can provide support based on a person’s faith tradition. They can also contact other counsellors, as needed or you may invite a member of your own faith community to provide spiritual support.



5. What to do if someone dies while you are with them

It may be that the person you care about dies while you are with them. If so, please tell the healthcare team, so that a doctor can come to confirm the death.

When you know the person has died, you do not have to do anything quickly. Take your time. If there are several people around the bed, you can all take the opportunity to say or do whatever feels right for you.

The healthcare team may ask you to leave the person for a few minutes. This can be a good time to contact other family members and friends.

The pastoral care team along with the healthcare team can support you at this time and explain what will happen next.

6. Looking after yourself

It can be difficult to think about minding yourself when someone you care about is dying. The healthcare team is there to support you. If you can, ask your family and friends for practical or emotional support.

Remember to eat and sleep when you can. Try to keep up your strength so you can spend time with the person who is dying or others who care about them.

Grieving

Grief is a natural process. It is what happens as people adjust to loss and change. Some people grieve before the person dies, as well as afterwards.



Even if the death was expected, many people feel shock and disbelief when it happens. You may appear to be coping but can also feel detached. Feelings and thoughts can come and go in waves. Grief does not happen in a set way.

The healthcare team including your GP can help you at this time.

Notes

This leaflet was developed by the joint HSE Hospice Friendly Hospitals (HFH) Oversight Committee.

Contact hfh@hospicefoundation.ie if you have any further queries or would like to provide feedback or comment on this booklet.

Copies can be ordered from www.healthpromotion.ie



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