

Caru

Supporting Care & Compassion
at End of Life in Nursing Homes

A continuous learning programme

When Someone You Care About is Dying in a Nursing Home

What to Expect




All Ireland
Institute of Hospice
and Palliative Care

caru.ie

Irish Hospice Foundation has made every effort to ensure the information contained in this resource is accurate and up to date. It is not intended as a substitute for medical advice, services, diagnosis and / or treatment.

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If someone you care about is dying in a nursing home, this information may help you know what to expect.

We understand this is a very emotional and challenging time for you. We hope this booklet will help make this time a little easier.

If there's anything you or the person living in the nursing home is concerned about, talk to the healthcare team (Nurses, GP, Healthcare Assistant etc.). You might be worried that now isn't a good time however, the healthcare team are available to provide information and answer any questions you might have.

We have included as much information as possible so you can be prepared for what to expect. Take your time reading this booklet and do ask any member of the healthcare team if you have any questions.

1. Introduction

When someone you care about is dying, it can be hard to know what to say or do. Sometimes it's hard to know how to comfort the person who is dying. We hope this booklet helps you understand what's happening if you're in this difficult situation.

Some deaths are sudden, and not every death is expected, so some information or sections may not apply to you.

This booklet includes information about:

- ☛ Changes you might see in the person who is dying.
- ☛ Talking about feelings.
- ☛ Talking about beliefs.
- ☛ Looking after yourself.
- ☛ Visiting during COVID-19 and influenza.
- ☛ Useful resources and information.

The person who is dying may already have told you and/or the healthcare team about what they want for themselves. 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. The information here focuses on the most common concerns and questions.

Remember, you can ask the healthcare team if you have any questions or concerns.

2. Changes you might see in the person who is dying

When a person enters the final stages of life, changes may affect their body or mind, or both. These changes are a normal part of the dying process. Sometimes 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 can be 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 don't happen in a set order and 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 the person by gently wetting their mouth and lips using small sponges. Applying a lip balm can also help. This will usually be enough to keep the person comfortable.

The healthcare team caring for the person can help too.

Becoming restless

Sometimes the person who is dying can become restless. They may appear anxious, or make repeated movements, like pulling at the blankets or their clothes. This is usually because of physical changes in their body and is part of the dying process. Medication can be given to relieve this, aid rest and help with sleep.

Talk to the healthcare team if the person's restless actions are upsetting them or you.

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 only. You can put extra blankets over the person's hands and feet to keep them warm and comfortable.

Sleeping more

When a person is dying, they may spend more time sleeping. When they're awake, they may be tired and sleepy, with little energy. They may not want to speak and may find it hard to concentrate. They may slip in and out of consciousness. Remember, this is normal.

Let the person relax and rest. It's important to remember that even when the person seems less conscious, they may still be able to hear you. You can reassure them by letting them know you're with them, by speaking or holding their hand.

Doing something you know will comfort them can also be useful. Speak softly but clearly and use the person's name.

Talk to the healthcare team if you're worried about the person's sleepiness.

Becoming confused

Occasionally, when awake the person may be confused about where they are, the time of day and who you or who they are. They may see or hear things that aren't there. They may also appear to speak with people who have already died.

Let them know you're with them by speaking, holding their hand or doing something you know will comfort them. Speak softly but clearly and use the person's name. You can gently reassure them that they're safe. Medication can be given to help the person if they're distressed, to aid their rest and help them sleep.

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 may change. It may get fast or become slow and shallow. The person may appear to be breathless. When they're near to death, there may be long gaps in a person's breathing. This isn't distressing to the person but is part of the dying process. 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 or throat. This noisy breathing will usually not disturb him or her, although it may be upsetting for you. This type of breathing happens because the person is no longer able to cough or clear their throat. It doesn't mean the person is in pain or is uncomfortable. Medication can be given to help ease the gurgling sound. It may not always be possible to ease the gurgling sound.

Talk to the healthcare team if you're worried about the person's breathing.

Having pain or discomfort

You may worry the person you care about is in pain or is uncomfortable. Not everyone experiences pain when they're dying but some may. The healthcare team will do all they can to make sure the person is comfortable. For example, this could be helping them to change position in bed.

The healthcare team will give medication as needed to ease the symptoms and relieve pain. The healthcare team will answer any questions or worries you may have about pain or medications.

Specialist Palliative Care Team

The healthcare team caring for your relative will work to ensure the person's comfort and dignity. If the person has a symptom or problem that's proving difficult to manage, advice from the local specialist palliative care team can be sought. If necessary, this team can visit the person to assess them and provide advice on increasing comfort.

What to do if someone dies while you're with them

It may be the person you care about dies while you're with them. If so, tell the healthcare team, so death can be confirmed.

When you know the person has died, you don't have to do anything quickly. It's a very personal moment and you should take your time.

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 healthcare team can support you at this time and will explain the next steps.

If you're the only person there when your loved one dies, sharing the details later can be important. Be prepared to tell the story and the role you and others played in it. Providing this information can be of great comfort.

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, may go through a range of emotions.

These may include:

- shock
- anger
- upset
- fear
- denial
- helplessness
- relief
- frustration
- acceptance

These feelings can come and go in any order. You and the person may go through all of them, 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 section aims to help you know what you can do to support the person when they are experiencing various feelings.

- 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

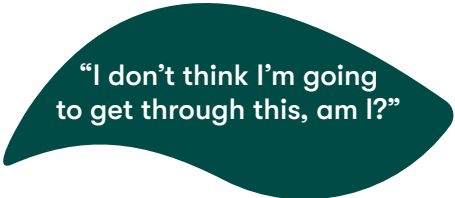
Sitting with the person and listening is important. Careful listening helps the person who is dying to share their feelings. It may also help you understand their concerns. Be respectful of what the person says. Try not to brush them off or change the topic. Most people just want to be listened to as they express their hopes and fears. They may also just want to know they are not alone.

Talking about dying and death

Talking about dying and death can be difficult. Many people find it hard to know what to say. People can also 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 be unsure of what to say. There is no right or wrong way to deal with this. Everyone is different.

It's 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:



“I don't think I'm going to get through this, am I?”

Or they may be more direct and ask:



“Am I dying?”

If you can, it's good to respond to any questions honestly. If you feel stuck for words you could say something like: “Are you worrying about something?” or “That's a big question, have you been thinking about that for a while?” or ‘Is there something on your mind you would like to talk about?’

Although it can be hard, it can be good to tell the truth. Some people don't want to focus on what lies ahead or talk directly about death or dying and their end of life. However, they may want to be reassured about what's happening and that they are getting care and support. When you're talking about death, it helps to listen carefully and to let the person speak freely. This may be about practical, emotional or spiritual matters.

It is important you look after yourself during these conversations. For more about this see Section 5.

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 don't 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. Use clear language they can understand such as 'dead' or 'died'. Terms such as 'gone' or 'gone to sleep' confuse and frighten children.

You might feel that you are protecting them by not telling them what is going to happen, but research shows that children who are included and informed will be more prepared and have less anxiety afterwards. Children find it hard to take in too much information at once, so break it down for them. Take small steps and add a little to the story each time.

Information about speaking with children about death and grief is available from our Irish Childhood Bereavement Network: www.childhoodbereavement.ie

Touch

You don't 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 dying person. Touch is a good way to let the person know you're there. This simple act can be invaluable and 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're there can bring 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's okay. Just knowing you're there and ready to listen can be reassuring. It can be good to be together in silence.

Letting go

Saying a final goodbye is never easy and most people find it difficult. Tears and talking about memories can be part of saying goodbye and can help you both to let go. Some people want to be there every moment, others find it difficult. Some people don't get to, or even want to, say goodbye. Some people don't cry.

It's important to remember there is no right or wrong way to behave. You must do what feels right for you. It's important to remember everyone is different and their relationship with the person who is dying is unique.

The healthcare team can give you support at this time.

4. Talking about beliefs

When seriously ill or dying, some 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 out loud.

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

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

Many nursing homes are supported by a spiritual leader who can help people with their religious and spiritual needs. You may also want to ask a member of the person's religious community to provide spiritual support.

5. Looking after yourself

It can be difficult to think about minding yourself when someone you care about is dying. Remember, the healthcare team is there to support you. Try to keep up your strength so you can spend time with the person who is dying and others.



You might find the following tips helpful:

- Remember to eat and to keep hydrated. Your body has needs, and you need to look after yourself.
- It's okay to feel overwhelmed and have feelings of loss even before the person has died. Reach out to people for support, share your feelings if you can.
- Keep conversations going with the people who are closest to you, like your family and friends. Even if those closest to you are not physically near, contact them and if possible, talk with someone each day. Having conversations keeps communication flowing and can remind you that people are thinking about you.
- If you get offers of help, allow yourself to accept them where you can.
- Keeping some routine, like mealtimes, can help. Try getting outside too, if possible.
- Seek information and support from the healthcare team. They are there to answer any questions and provide some support to you.

Grieving

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

Even if death was expected, many people feel shock and disbelief when it happens. You may seem to be coping but can also feel you're going through the motions. Feelings and thoughts can come and go in waves. Grief also doesn't happen in a set way and it takes time.

The healthcare team and your GP can help you at this time by providing some information and advice. See section 7 for helpful resources.

Grief and COVID-19

You may not have been able to spend time with person you care about prior to or at the time of their death. This may make it more difficult to feel that the death is real. It might also bring up feelings of regret, anger or even guilt.

COVID-19 meant people had to make sacrifices to protect the health of others, as well as themselves. Try not to dwell on the painful aspects of that time. Remember that a relationship is made up of all of life's shared times, this can never be taken away from you.

6. Visiting during an outbreak of COVID-19 or influenza

COVID-19 is an illness that can affect a person's lungs and airways. It's caused by a virus called coronavirus. Flu is a contagious respiratory illness caused by influenza viruses that infect the nose, throat, and sometimes the lungs. Residents of nursing homes are a particularly vulnerable group who may be a risk of serious illness if they develop COVID-19 or flu.

Please speak to the person's nominated support person and contact the nursing home directly for the most up-to-date information and advice about visiting during an outbreak of COVID-19 or visit www.hpsc.ie for updated guidelines.

7. Useful resources and information

IHF Bereavement Support Line

Free phone **1800 807077**. Available Monday to Friday, 10am-1pm. In partnership with the HSE. Our Bereavement Support Line is for any bereaved adult or those supporting them.

IHF Bereavement & Loss Hub

As a national leader in the development of bereavement care, we are working in collaboration with bereavement care providers and charities to provide information, resources and programmes for individuals, families, communities and workplaces. Visit www.bereaved.ie

Caru

Caru – Supporting Care & Compassion at End of Life in Nursing homes is a continuous learning programme that supports nursing homes and their staff in the delivery of palliative, end-of-life, and bereavement care to residents. This in turn will support an enhanced quality of life for residents, a good death, while easing the bereavement process for families and staff. Visit www.caru.ie



Think Ahead

Think Ahead is a tool to support advance care planning and end of life. It helps you document your healthcare choices and personal wishes. Advance Care Planning is thinking about, talking about, and recording your choices, values, and preferences for your care at end of life. Discussing what you want with your loved ones, or with your GP or healthcare team, is an important part of advance care planning. It prepares you and others for a time when you may no longer be able to communicate those decisions. Think Ahead is available from thinkahead.ie

Children's Grief

Our Irish Childhood Bereavement Network has advice on talking to children about death and grief.

Visit www.childhoodbereavement.ie

Citizen Information

Citizen Information Board has published information on a range of practical concerns you may have when someone close to you dies. Visit citizensinformation.ie

HSE

This HSE website has the most up-to-date information on COVID-19 <https://www2.hse.ie/conditions/covid19/>





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