

When someone you care about is dying in a nursing home - what to expect.



If someone you care about is dying in a nursing home, this information may help you know what to expect. You may be worried about many things, including COVID-19. We understand that this is an emotional and challenging time for you. We hope this resource will help to make this time a little easier by providing helpful and useful information.

Much of the information here has been adapted from the Health Service Executive (HSE) and Hospice Friendly Hospitals Programme (HFH) booklet: **When someone you care about is dying in hospital – What to expect**. This booklet can be accessed here: https://hospicefoundation.ie/wp-content/uploads/2020/04/When-someone-you-care-about-is-dying-in-hospital_What-to-expect.pdf



Talk to the healthcare team (GP, Nurses, Healthcare Assistants, etc.) if there is anything worrying you or the person living in the nursing home. You might be worried that now is not a good time to do this. However, the healthcare team are available to provide information and answer any questions you might have. We understand that COVID-19 is a source of stress and anxiety now.

This resource includes some information about COVID-19 and links to HSE websites. This is where the most up to date and reliable information about COVID-19 can be found. This is followed by information about visiting a nursing home during the COVID-19 crisis. Also included here is practical information about the physical changes that can happen as a person is dying. Not all the changes explained here happen as a person dies. In addition, not all the things suggested to provide comfort and reassurance may be possible at this time due to COVID-19 restrictions. We have included as much information as possible so you can be prepared about what to expect. Take your time reading this information and remember to ask any member of the healthcare team if you have questions.

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, especially when visiting is restricted. This resource aims to help you to understand what is happening when you are 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 resource includes information about:

- Visiting during COVID-19
- Changes you might see in the person who is dying
- Talking about feelings
- Talking about beliefs
- Looking after yourself
- 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. This information resource deals with the most common concerns and questions. You can ask the healthcare team if you have any other questions or concerns.

2. Visiting during COVID-19

COVID-19 is an illness that can affect a person's lungs and airways. It is caused by a virus called coronavirus. Residents of nursing homes are a vulnerable group who may be at risk of serious illness if they catch COVID-19. Current guidance from the HSE on COVID-19 is that all visiting should be restricted. This is the best way to reduce the risk of you and other people getting COVID-19. Exceptions will be made on compassionate grounds, such as at the end of life. Contact the nursing home directly for up-to-date information and advice about visiting during this time.

Staff in the nursing home will work to ensure that a person is comfortable and does not die alone. The Irish Hospice Foundation recommend that at least one person be facilitated to be present with the person who is dying. If you are unable to visit a person who is dying in a nursing home, the Irish Hospice Foundation Care & Inform *What can I do when I can't visit a loved one who is dying?* resource may be helpful (see Section 7 Useful resources and information).

Stay in contact with the nursing home. They will provide guidance for you on how to remain engaged. This might include using iPads, tablets or phones for voice or video calls for you to stay connected. If you are visiting, you may be required to wear a special disposable gown over your clothes or use a face mask. Staff will show you what to do before you go into the room as well as when you come out.

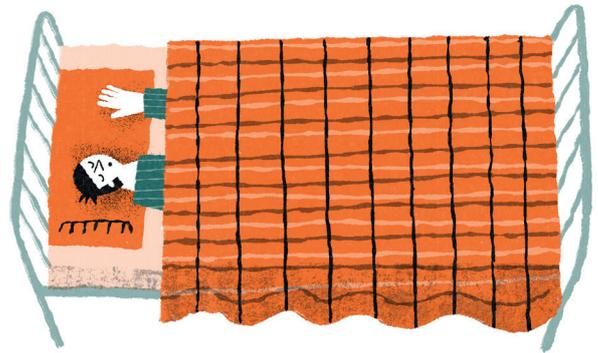
3. Changes you might see in the person who is dying

This section explains some of the changes that are common when a person is close to death. When a person enters the final stages 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 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 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, such as 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. 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

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 and may find it hard to concentrate. They may slip in and out of consciousness. This is normal.

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Let the person relax and rest. Do not ask lots of questions as this may agitate the person. It is 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 that you are with them by speaking or holding their hand. Doing something that 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 are worried about the person's sleepiness.

Becoming confused

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

Let them know you are with them by speaking, holding their hand or doing something that you know will comfort them. Speak softly but clearly and use the person's name. You can gently reassure them that they are safe. Medication can be given to help the person if they are distressed. 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 are near to death, there may be long gaps in a person's breathing. This is not distressing for 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 to listen to. This type of breathing happens because the person is no longer able to cough or clear their throat. It does not mean the person is in pain or is uncomfortable. Medication can be given to help. 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 is uncomfortable. Not everyone experiences pain when they are dying but some may. The healthcare team will do all they can to make sure the person is comfortable. This could be, for example, by 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 with the aim of ensuring the person's comfort and dignity. If the person has a symptom or problem proving difficult to manage, advice from the local specialist palliative care team can be accessed. 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 are with them

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

When you know the person has died, you do not have to do anything quickly. It is 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 are 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.



4. 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 and 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.

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 important. 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 also just want to know that 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 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 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: “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 is 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?”

Although it can be hard, it can be good to tell the truth. Some people do not want to focus on what lies ahead or talk directly about the end of life. However, they may want to be reassured about what is happening and that they are getting 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.

It is important that you look after yourself during these conversations. For more about this see section 6.

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. Use clear language they can understand such as ‘dead’ or ‘died’. Terms such as ‘gone’ or ‘gone to sleep’ confuse and frighten children. Information about speaking with children about death and grief is available from the Irish Childhood Bereavement Network: <https://www.childhoodbereavement.ie/>

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 dying person. Touch is a good way to let the person know you are there. This simple act can be valuable. It may also be comforting for both of you.

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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 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 OK. Just knowing you are 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 do not get to, or even want to, say goodbye. Some people do not cry. It is important to remember there is no right or wrong way to behave. You must do what feels right for you. It is important to remember that everyone is different and their relationship with the person who is dying is unique. The healthcare team can give you support at this time.



5. 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 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. You may find 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.

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. Try to keep up your strength so you can spend time with the person who is dying and others. The following tips might be useful to you:

- Remember to eat and to keep hydrated. Your body has needs, and you need to look after yourself.
- It is OK to feel overwhelmed, as well as to 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 be helpful. 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 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 death was expected, many people feel shock and disbelief when it happens. You may appear to be coping but can also feel you are going through the motions. Feelings and thoughts can come and go in waves. Grief does not 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 to refer to.

Grief and COVID-19

You may not have been able to spend time with your loved one 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.

It can be hard to find meaning, peace or comfort at times like this. COVID-19 has meant people have had to make sacrifices to protect the health of others, as well as themselves. While you may be thinking about all that has happened including death, try not to dwell on these painful aspects. A relationship is made up of all of life's shared times, this can never be taken away from you.

7. Useful resources and information

Here are some useful websites that provide support and information.

The Irish Hospice Foundation Care & Inform Hub has resources and information that have been developed in response to COVID-19. Resources are available about bereavement, grief and loss during the Covid-19 restrictions. These resources, and more are available: <https://hospicefoundation.ie/covid19careandinform/>

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

The HSE has information about caring for someone with COVID-19, including a list of do's and don'ts: <https://www2.hse.ie/conditions/coronavirus/self-isolation-and-limited-social-interaction.html>

This resource provides support and tips, if you are unable to visit someone who is dying because of COVID-19 restrictions: <https://hospicefoundation.ie/wp-content/uploads/2020/04/What-I-can-do-when-I-cant-visit-a-loved-one-who-is-dying-during-Covid19.pdf>

The Irish Hospice Foundation CEOL programme is a quality improvement programme for nursing homes and residential centres focused on improving end of life care. Information about CEOL (compassionate end of life) is available here: <https://hospicefoundation.ie/healthcare-programmes/ceol/>

Information, videos and reflections on grief and bereavement are available from the Irish Hospice Foundation: <https://hospicefoundation.ie/bereavement-2-2/bereavement-resources/>

The Irish Childhood Bereavement Network has advice on talking to children about death and grief: <https://www.childhoodbereavement.ie/>

