

Caring for someone at home who is nearing the end of life



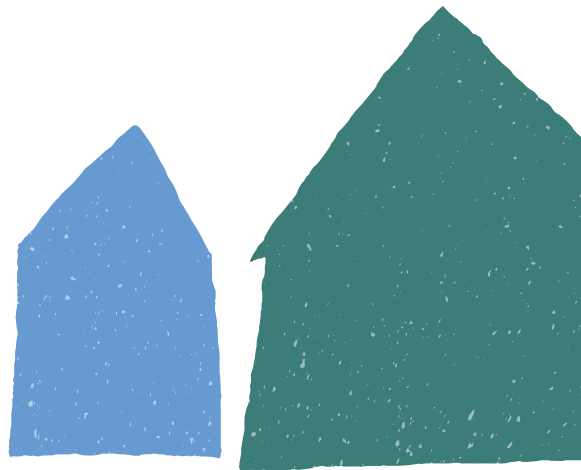
Irish
Hospice
Foundation

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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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01.

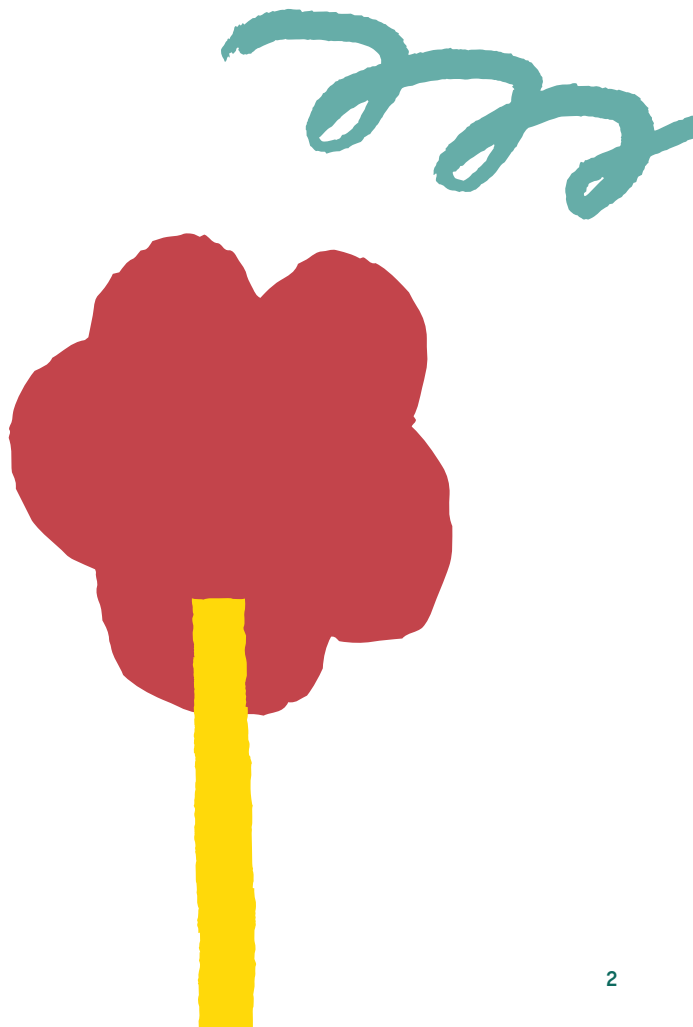
Introduction

Much of the information here has been adapted from the booklet, **When someone you care about is dying in hospital – What to expect.** It contains information about the physical changes that happen as a person is dying. You can find it on our website www.hospicefoundation.ie.

We have used the information here from what's available from the Health Service Executive (HSE) and our Hospice Friendly Hospitals Programme (HFH). We've also consulted with our Primary Palliative Care Steering Committee, the Irish College of General Practitioners, clinicians, Care Alliance Ireland, and the All-Ireland Institute of Hospice and Palliative Care Voices4Care group, to ensure all the information is accurate and reliable.

If someone you know is living with a terminal illness, you may be concerned about many things, including COVID-19. If there's anything worrying you, or the person you're caring for, talk to a healthcare professional like your GP, Public Health Nurse or Community Social Worker. You might be concerned that now isn't a good time to do this, however, services are still operating, and GPs can be contacted by phone.

Tips on staying in contact with your GP and other community-based healthcare professionals are included in this booklet. This is followed by practical information about providing end-of-life care in your home. We also provide answers to some of the questions you might have about caring for someone at home who is nearing the end of life during COVID-19.



02.

Staying connected with your GP and community-based healthcare professionals

It's important to stay connected with the healthcare professionals who can support you.

- Have you contacted your GP, Public Health Nurse and/or the local Community Specialist Palliative Care team?
- Have you let your GP know what's happening and what support you need? Your GP can provide advice on managing pain and other common symptoms at the end of life.
- Do you know the best hours to contact your GP? It's best to contact them earlier in the day rather than later, as you're most likely to make contact with them that way, and also as contact hours may be reduced because of COVID-19.
- Do you know how to contact the GP Out-of-Hours service? Try to contact your own GP first, if possible.
- Remember if an emergency occurs, dial 112 or 999.

- Have you contacted your Pharmacist about the medications you'll need at home? Ask about home deliveries too. Your GP or Pharmacist will help with keeping a regularly updated list of all medications at home, which is important.
- Have you asked the Public Health Nurse or Community Specialist Palliative Care Team about getting other supplies and equipment you may need, like incontinence wear?
- Consider asking your GP to send you any relevant information to keep in the home. This might include a list of medications, Summary Medical History and a Care Plan.

How can I get Specialist Palliative Care services at home?

Your GP and Public Health Nurse are your most important healthcare resources. They are continuing to provide care, advice and support during COVID-19.

Your local Community Specialist Palliative Care Team can offer advice about end-of-life care. Your GP or Public Health Nurse can put you in touch with them, after they have talked with the person living with the illness and/or their carer(s).



03.

Supporting the person who is dying at home

Other supports are available to help people who are nearing the end of life at home. These include our free Nurses for Night Care service (for people with illnesses other than cancer who wish to die at home) and the Irish Cancer Society's free Night Nursing service (for people dying at home with cancer).

Information about Nurses for Night Care and the Night Nursing service are available below:

- Irish Hospice Foundation Nurses for Night Care Service: www.hospicefoundation.ie
- Irish Cancer Society Night Nursing Service: www.cancer.ie



You might also find our resource, **Practical Information: Caring for someone at the end of life at home** helpful. It's available on our website. www.hospicefoundation.ie

Being with a person who is dying at home

- If you're well yourself, it's good to sit in the room with the person and continue to speak to them and to have conversations, if they're interested.
- Sitting with the person and listening is very important. Careful listening helps the person who is dying 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.
- If they can respond, provide the person with a phone, iPad/tablet to allow them to stay connected. Even if they can't respond, they may enjoy being able to see or hear people who contact them.
- Some people might need to be transferred to a hospital, hospice or nursing home at the end of life, due to changing medical needs. This can be upsetting but could also be the right thing for everyone.

04.

What to expect if someone is dying at home

Caring for a dying person at home is very rewarding, but it can also be very hard.

Things to consider as a person is dying:

- 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. Applying a lip balm can also help. This will usually be enough to keep the person comfortable.
- Sometimes the person who is dying can become restless. They may be anxious, or make repeated movements like pulling at their blankets or clothes. This is usually because of physical changes in the body.
- 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 isn't reaching their arms and legs. You can put extra blankets over the person's hands and feet to keep them warm and comfortable.
- 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. They may slip in and out of consciousness. This is normal.
- As they become evidently weaker and tired, it's a good idea to limit and reduce visiting.

(HSE & IHF, 2018 *When someone you care about is dying in hospital – What to Expect*)

05.

Specific considerations for visitors during COVID-19

Public Health guidance about visiting during COVID-19 is there to protect people from getting the virus. The guidance may change so be sure to keep up to date with guidelines available from the HSE and Government.

If people do visit:

- Visits should be kept as short as possible.
- Maintain the 2 metre (6ft) rule for social distancing as best you can.
- Face coverings should be worn in line with guidelines.
- Make sure everyone visiting the house washes their hands carefully when they arrive and when they leave.
- Have soap and towels specially for visitors, if possible.
- **People who have any illness, or who are feeling unwell, should not visit.**

What can I do if I can't visit someone?

Current HSE and Government guidelines should be followed. Make sure everyone who wants to visit understands this.

Remember:

- Although upsetting, not being able to visit isn't your fault. It's the best way to reduce the risk of others getting COVID-19.
- You may be able to text, phone, video call or keep in touch via social media. Writing a thoughtful letter or card is also a good way to let someone know you're thinking of them.
- Assisting with caring tasks such as grocery shopping or cooking meals can be a good way to stay involved, even if you can't visit in person. Ask the person and those close to them what would help them most.

You might find our resource **What can I do when I can't visit a loved one who is dying?** helpful. It's available on our website www.hospicefoundation.ie

06.

Caring for yourself

Caring can be lonely at any time, but might be especially lonely right now.

Worrying about what will happen is normal. It can also be very upsetting and tiring. It's important to stay in touch with other people and ask them to help you.

- Even if people can't visit you, allow them to offer their support in different ways; texts, emails and messages through social media, phone and video calls are all great ways to stay in touch.
- Remember to eat and to keep hydrated. Your body has needs and caring is hard work.
- It's okay to feel overwhelmed and to have feelings of loss even before the person has died. Reach out to people for support and share your feelings, if you're able.
- Plan for the eventuality that your family and friends can't visit. Think about who can help with day-to-day caring duties and how you can stay in touch.
- Keep conversations going with the people who are closest to you, like your family and friends. Even if those closest to you aren't physically near, contact them and talk with someone each day, if you can. 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. Be open to suggesting to people the ways they can best help you. Remember, people **do** want to help you.
- Keeping some routine, like mealtimes, can help. Having a fixed bedtime and getting-up time is good too. Try to stick to your normal routine as much as possible. Try getting outside too, if possible.
- If there are children in your family, check in with them. Answer questions honestly and be consistent. Don't dismiss them. Children's information needs and responses will be age specific. Children may appear sad and happy in the space of minutes.
- Try to limit how much news and social media you consume, particularly before bedtime. When you're feeling very sad, news reports can be distressing.



07.

Planning ahead

It's important to think and talk about the end of life. Opening a conversation about a person's values and wishes can help them maintain control over their end-of-life care.

Simple conversation openers include:

- *'If you were to become very unwell and unable to speak for yourself, is there anything you'd like me to know about your wishes and preferences?'*
- *'Is it okay to write some of this down so I don't forget?'*
- *'Is there anything you don't want to happen at the end?'*
- *'Is there anything you would like to happen?'*
- *'Is there something I should know that I don't know?'*

Don't rush this process. Take your time and talk it through a little bit at a time, if that seems best. Consider doing it a second time if you feel it may be useful to do so.

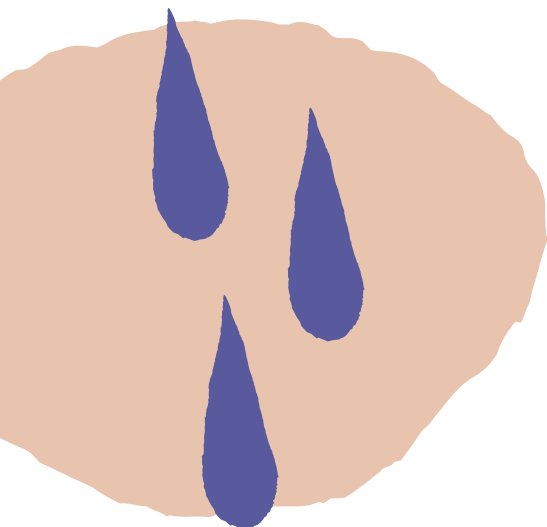
Some people may not want to talk about their dying or their death. This is okay. Let them know you understand that it's not easy and maybe they'll want to talk about it later.

Our Think Ahead form helps people to think about their end-of-life preferences, to talk about them openly and write them down. You can fill in as much or as little of the form as you like. It really depends on how much information you want to share and what's important to you.

Think Ahead also contains an Advance Healthcare Directive which sets out:

- your wishes in relation to refusing treatment if you're unable to speak for yourself.
- who you want to speak for you (a trusted person) if you can't speak for yourself.

Think Ahead is available to download for free from our website or you can order a physical copy. www.hospicefoundation.ie/thinkahead



08.

Answers to COVID-19 questions you may have

What is COVID-19 and where can I access reliable information about it?

COVID-19 is an illness that primarily affects your lungs and airways. It's caused by a virus called coronavirus. It's important to access reliable and trustworthy information in relation to COVID-19. The HSE has lots of practical and useful information in relation to COVID-19. www.hse.ie

Will the Community Specialist Palliative Care Team still come to my home?

HSE community services, including the service provided by the Community Specialist Palliative Care Team, are still working and available during COVID-19. There may be some changes with home visits. Your Team or local hospice can provide you with up-to-date information.

I'm the main carer for a person who is dying at home. What should I do if I think I have COVID-19?

Follow the guidance provided by the HSE and contact your GP for information and advice.

If I get COVID-19, will my Think Ahead form be valid?

Yes. The Advance Healthcare Directive part of Think Ahead is valid and legally binding, if you have:

- filled in the Advance Healthcare Directive (Part 2.2).
- had it signed and witnessed by two people over 18 (at least one of whom should not be a family member).

It's vital you tell people you trust, such as your family, close friends and/or doctors, that you have made an Advance Healthcare Directive.

It's also important to remember that what's written in your Advance Healthcare Directive will only apply if you lose capacity and are unable to speak for yourself.



Useful resources

IHF COVID-19 Care & Inform

Our Care & Inform Hub has been specially developed to support those facing dying, death and bereavement during COVID-19. It includes information on grieving in exceptional times, planning a funeral, supporting children/young people who are grieving and other supports for carers. Visit www.hospicefoundation.ie

IHF Bereavement Support Line

Freephone 1800 80 70 77. Available Monday to Friday, 10am-1pm. In partnership with the HSE. Our Bereavement Support Line is for any adult grieving in these exceptional times.



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

Family Carers Ireland

Family Carers Ireland offers useful advice. www.familycarers.ie

Irish Cancer Society

The Irish Cancer Society booklet **A time to care - Caring for someone seriously ill at home** is a useful guide. www.cancer.ie



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