When Someone you Care about is Dying at Home

What to Expect

Practical information when caring for the person



Irish Hospice Foundation
To die and grieve well wherever the place



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Why we created this booklet

Irish Hospice Foundation (IHF) receive regular enquiries from both members of the public and healthcare professionals seeking information about end-of-life care. We created this booklet to respond to and help with these enquiries. This need was also highlighted through Irish Hospice Foundation's Dying Well at Home Focus Group Report in 2023. IHF is working to put in place the recommendations from the report through our Dying Well at Home programme. This booklet forms part of the recommendations.

Contributors in IHF

IHF's Dying Well at Home team wrote this booklet with significant contribution and oversight from other IHF teams including Healthcare, Public Engagement, Bereavement and Education and Marketing and Communications teams. These teams have significant expertise in, and experience of, working in healthcare settings. Team members have worked at all levels, including management, general and specialist nursing, social work, health promotion, bereavement services and education for medical and other healthcare staff.

The Dying Well at Home Team at IHF would like to thank all who collaborated in the development of this booklet.



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See pages 42-47

Welcome

Many people would like to stay in their own home or in a relative's or friend's home when they are approaching the end of their lives. However, there are many reasons why this is not always possible, and many people die in a hospital, a hospice or a nursing home. Some people, however, will manage to be at home in the final months, weeks and days of their lives.

These people can be supported to 'die well' at home by a professional carer, and they may also be cared for by a family member or friend. People often take on the role of a carer without any training and with little knowledge of what being a carer at end of life involves.

That is why, our Dying Well at Home team at Irish Hospice Foundation has developed this booklet. We want to support people like you who are caring for a person who wishes to die at home. To support you, we provide useful information and practical tips to help you in your caring role. The person who is dying might be your loved one, a family member, a relative, a friend or someone else you are caring for at home. **To make it easier, we will refer to the person who is dying as 'the person' in this booklet.**

Involving the person

We know it is very important that the person who is ill or dying is involved – as much as they can be or want to be – in conversations about their own care. There is a lot of information available for the person on our website and leaflets. However, in this guide we do not speak directly to the person. Instead, **we speak and have written directly to you, their carer**.

Aim of this booklet

We understand that caring for someone at home can be both a challenging and rewarding experience. We also know that the right help needs to be in place to support a person's wish to die at home and also to support those people who are providing end-of-life care.

The aim of this booklet is to provide you with tips and information on:

- what is needed to provide end-of-life care
- the physical changes that happen as the person is dying
- how to provide care as the person is dying
- how to access supports
- what to do after the person has died at home
- how to you look after yourself

This booklet is not designed to provide or replace medical advice. All medical care specific to the person's illness should be planned by the medical team who oversee the person's treatment.



Part 1

Getting ready to care for the person at home

When a person chooses to die at home, you need to do many things to support their wish. This booklet can help you to get ready to provide the care the person needs.

Talk to their medical team and social worker: If the person is coming home from hospital, discuss this with their medical team and the social worker. This will help you to prepare and have everything that you need in place.

Talk to their GP: You also need continued support and guidance from the person's General Practitioner (GP) and Public Health Nurse, who can support end-of-life care at home.

If the person's symptoms are becoming more difficult to manage: If the person develops symptoms that become more difficult to manage, they will need to be referred to a Community Palliative Care Team who provides specialist care. This includes pain control and management of other symptoms as the person is nearing the end of their life. We will discuss this in more detail later in this booklet.

Your medical and palliative care teams will do their best to help you care for the person for as long as possible in their home. However, you should also prepare for a situation where the person might need to be transferred to a hospital, a hospice or a nursing home. If this happens, you might find this upsetting, but it could also be the right thing for everyone.

We hope that this booklet provides information and support so you can provide care for the person in their home for as long as that's possible if this is their wish.

Additional information, eLearning and support around end-of-life care is available on IHF's Information and Support Line, see pages 42-47 for details.

Getting the home ready

Choose the best room: Whether someone is moving into your home or is staying in their own home, choose the room that is best for their care.

Think about how easy it is to get in and out of the room. If possible, choose a room on the ground floor. This can help if the person's mobility gets worse as they near the end of their life. It can also be very useful if the room is close to a bathroom and kitchen, as this makes it easier for the person to use the bathroom or get a glass of water, especially in the middle of the night.

Clear out any clutter: Clear out any clutter from the rooms and spaces where the person you are caring for will be. This will make it easier to move around the room.

To reduce the risk of falls, keep pathways clear and remove any:

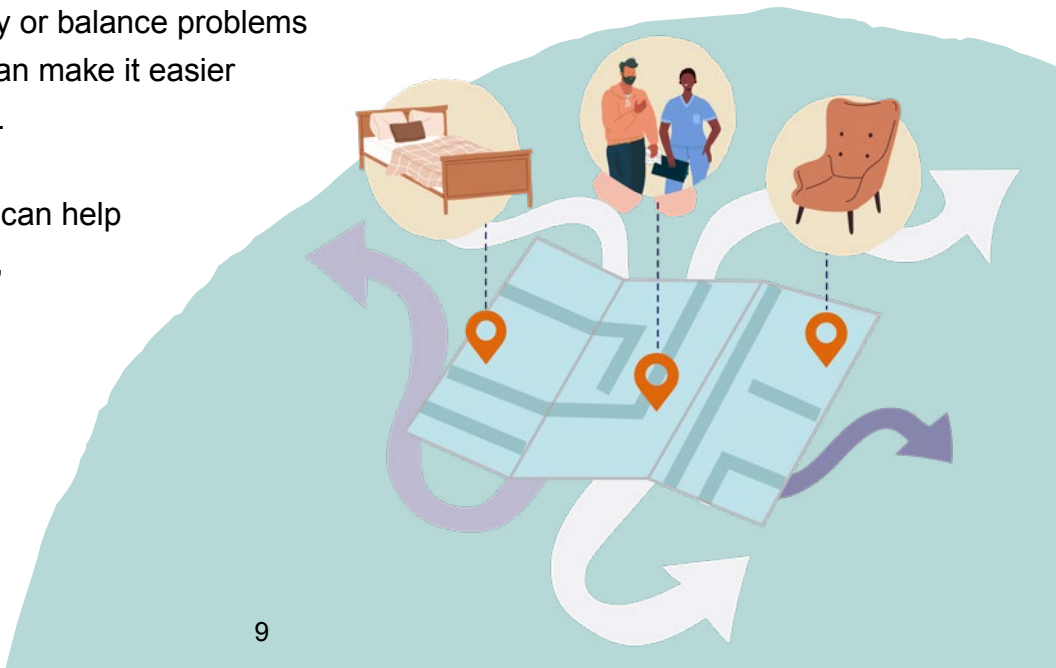
- electric cables
- loose rugs
- shoes
- pet food bowls
- other items that are not needed

Get advice about equipment: Don't try to organise this on your own. Get advice from your Primary Care Team and the Public Health Nurse about what equipment you need and how to choose and use it correctly.

Make daily tasks easier: Having equipment installed in your home, such as safety rails near the sink, bathtub and/or shower, and toilet can make it easier to support a person with daily tasks like dressing and bathing.

Using safety equipment can also help keep the home accessible to the person you are caring for, for as long as possible. Even if the person you are caring for does not have mobility or balance problems now, planning for them can make it easier if they need support later.

Occupational Therapists can help you by offering guidance, information, and support about helpful equipment for you and the person you are caring for.



Life-limiting illnesses

A life-limiting illness is any disease, condition or illness that is progressive (getting steadily worse), and that cannot be cured. A person may live with a life-limiting illness for many years or for a much shorter period.

In this booklet, we focus on the last few months and weeks of a person's life-limiting illness, when they are near the end of their life. We call this period end of life.

Palliative care cannot cure a person. It is supportive care that can be offered throughout a person's life-limiting illness. This care can vary at different stages of their illness, as different levels of palliative care can be provided. More specialised palliative care may be needed as the person's illness progresses.

Primary Care Team: A person's Primary Care Team is a team of healthcare workers who can support them at home as they live with a life-limiting illness, and particularly as they near the end of their life. This team will usually include their General Practitioner (GP), General Practice Nurse and the Public Health Nurses (PHNs). It can also include Community Registered General Nurses (RGNs), carers, hospital-based healthcare professionals, pharmacists, counsellors, and many other allied health professionals.

Community Palliative Care Team: The Primary Care Team can ask the Community Palliative Care Team (who provide specialist care and advice) to become involved if necessary. This team is needed when a person's symptoms become more complex or difficult to manage, and the team may need, for example, to provide stronger pain relief and other medications.

These teams can be based in a hospital or in the community, though most Community Palliative Care Teams are based at your local hospice. The team will visit the person in their home or wherever they are being cared for. They will assess or check the person and decide on the best way to manage as many of their symptoms as they can. They will then contact the GP if they need to change the medicine or if another treatment is needed. Later, the Community Palliative Care Team can guide you about the care that the person will need as they are nearing end of life.

Most palliative care services are free for all patients and their families in the Republic of Ireland.

Financial supports for people at end of life

Caring for someone at home can be very stressful and expensive, but there may be some financial supports available, depending on the person's circumstances. Their Public Health Nurse and social worker should be able to advise you on this.

Long-Term Illness Scheme

There are schemes you can apply for through the HSE such as the Long-Term Illness Scheme where you can get some medicines and medical appliances for free.

To learn more about the Long-Term Illness Scheme, go to **https://www2.hse.ie/services/schemes-allowances/lti**.

Other financial support

Here we tell you about two forms of financial support that are available to everyone with a life-limiting illness:
(1) Drug Payment Scheme Card
(2) Emergency Medical Card (available to any person who has fewer than two years to live)

(1) Drugs Payment Scheme Card
A person can apply for a Drugs Payment Scheme Card if they pay more than a certain amount (known as a threshold) each month for approved drugs, medicines, and appliances. If they have a medical card, they do not need a Drugs Payment Scheme Card. Please note the threshold can change each year.



You will find more details about this scheme by visiting the HSE website under the 'Services' section, or follow this link:
https://www2.hse.ie/services/schemes-allowances/drugs-payment-scheme/card/

(2) Emergency Medical Card
Emergency Medical Cards are currently available to anyone who:

- has a life-limiting illness and has been told by their doctor or consultant that they have 24 months or fewer left to live
- is receiving end-of-life care or treatment
- urgently needs a medical card because they have urgent ongoing care

You can get an Emergency Medical Card for the person if needed without a means test, but a healthcare professional must apply for the card. They can apply in one of two ways. It will depend on the stage and prognosis of a person's illness (how the person's illness is likely to progress).

If a person has a terminal illness and has been told they have 24 months or fewer to live, their hospital consultant will send the HSE an Emergency Medical Card application form. The consultant must send a detailed medical report with an application form, including the person's diagnosis, planned treatment and prognosis.

If a person is receiving end-of-life treatment and has been told they have less than 12 months to live, their social worker, hospital consultant or GP will send the HSE a medical report and a completed end-of-life care medical card application form.
https://www2.hse.ie/services/schemes-allowances/medical-cards/other-types-of-medical-card/emergency-medical-cards/

When a person's application has been processed, their medical card number will be active within 24 hours. A person's GP, pharmacy and hospital staff will see that their card is active on their systems. This means they can access medical card services while they wait for their card in the post. They should receive their card in the post within 10 working days.

For more information, you can:

- Phone the National Medical Card Unit on **0818 22 44 78** (LoCall)
- Email: **clientregistration@hse.ie**

HSE Home Support Service

The HSE Home Support Service (formerly called the Home Help Service or Home Care Package Scheme) aims to support older people to remain in their own homes for as long as possible and to support informal carers.

The Home Support Service provides you with support for everyday tasks including:

- getting in and out of bed
- dressing and undressing
- personal care such as showering and shaving

The support you will receive depends on your individual needs. These supports will be provided by the HSE or by an external provider, approved by the HSE.

Costs

The Home Support Service is free. You do not need a medical card to apply, and your income will not be assessed. However, if you arrange additional home supports, over and above the level funded by the HSE, you will have to pay for these.

Who can apply?

The Home Support Service is available to people aged 65 or over who may need support to continue living at home or to return home following a hospital stay.

Sometimes exceptions are made for people younger than 65 who may need support. For example, people with a disability or with early onset dementia. For further details, see links below.

- **https://www.hse.ie/eng/home-support-services/apply-for-home-supports-services/applying-for-home-support- services.html**
- **https://www.hse.ie/eng/home-support-services/apply-for-home-supports-services/home-support-information-booklet-application-form.pdf**

Carer's Allowance

Carer's Allowance is a payment you get through social welfare if you care for someone full time. You have to apply for it and it's means-tested. This means social welfare will look at your income to see if you need financial assistance or not.

The person you are looking after must need full-time care. They may need care because of their age, disability, or a physical or mental illness.

To get Carer's Allowance you must apply through the Department of Social Protection. The HSE does not manage this scheme.

- **www.citizensinformation.ie/en/social-welfare/carers/carers-allowance/**
- **https://www.gov.ie/en/service/2432ba-carers-allowance/**

Carer's Benefit

Carer's Benefit is paid to people who leave work or reduce their hours to care for a person in need of full-time care. To get Carer's Benefit, you must be under 66 and have enough social insurance (PRSI) contributions. You can get Carer's Benefit for 2 years (104 weeks) for each person that you are caring for, and you can take the 104 weeks all together or any number of separate weeks up to a total of 104 weeks. While receiving Carer's Benefit or Carer's Allowance, you may be eligible for additional allowances. For more information on your entitlements, please visit **citizensinformation.ie**

- **www.citizensinformation.ie/en/social-welfare/carers/carers-benefit/**
- **www.gov.ie/en/service/455c16-carers-benefit/**

Advance Care Planning

We all value different things in life and have preferences around what kind of care we would like to receive in the future. **Advance Care Planning** involves thinking about, talking about, and recording our choices, values, and preferences for our care at the end of our life. In this way, we can make an **Advance Care Plan**.

When caring for someone at home, make sure to check if they have an Advance Care Plan or if they have recorded or written down what their healthcare choices and personal preferences are for their end-of-life care and where you can access this information. This is key if the person's illness means that they are no longer able to speak for themselves.

An Advance Care Plan makes sure that the person you are caring for receives the care that is most comfortable for them. You can learn more about **Advance Care Planning** at **thinkahead.ie** or by scanning this QR code:

IHF's Think Ahead Planning Pack is available to download for free at thinkahead.ie or you can order a printed pack by calling **(01) 6793188** which costs €5 plus postage.

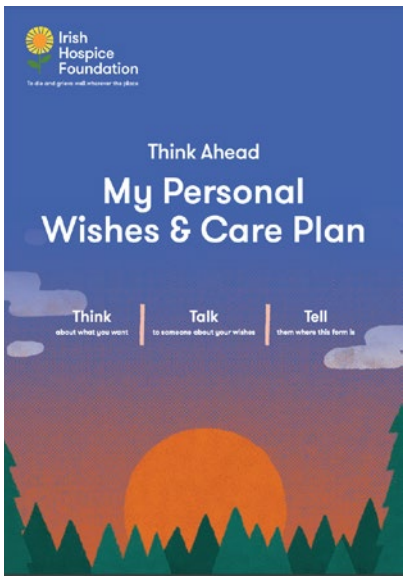
If you are unsure if the person you are caring for has discussed or written an Advance Care Plan, you can check with their GP or a close family member.

If there is no plan in place and the person you are caring for can make decisions for themselves, you or their doctor can ask them if they would like to talk about their care wishes. You can ask them if they want their preferences written down and who they want to share this information with. These talks can be emotional, so bear in mind that the person might not be ready to talk about it.

Think Ahead is a practical tool developed by Irish Hospice Foundation to think about, discuss or write an Advance Care Plan. The **Think Ahead Planning Pack** can guide conversations about an Advance Care Plan, and help record the person's preferences.

Think Ahead Planning Pack

Each **Think Ahead** Planning Pack has three documents. We clearly set out all the steps and information about **Advance Care Planning** in these documents.







Each of these documents are explained below:

1. Personal Wishes and Care Plan
This document can help make sure that the person is cared for in ways that meet their physical, emotional, spiritual, cultural, and personal wishes. However, this plan is not legally binding.

The plan includes your financial and legal information, as well as information on what you would like for your funeral. You can read more about this by going to www.thinkahead.ie and choosing the option “Personal Care”.

2. Advance Healthcare Directive
In the Advance Healthcare Directive, the person can:

- record their requests
- record any healthcare treatments they refuse (do not want to have) in the future
- appoint or name someone to speak on their behalf if they can’t in the future

This document is legally binding when signed and witnessed properly. You can read more about can read more about this by going to **thinkahead.ie** and choosing the option “Healthcare.”

3. Medical Summary Form

This document is where a person can summarise the choices they have made in their Personal Wishes and Care Plan and Advance Healthcare Directive.

The Medical Summary Form can be shared with their GP, carer, or specialist teams. The form is a quick reference guide for medical professionals. You can ask your GP or specialist team to make a copy and place it in the medical file. You can also store this document somewhere that is easy to access in the person's home or where they are being cared for.

Cultural Differences

Each of us has our own identity. Our identities come from our own life experiences, cultural backgrounds, relationships, religion, and many other factors. These individual traits and beliefs can shape how we see caregiving, care needs, pain management, self-care, and end-of-life experiences, including grief and bereavement.

Your cultural, spiritual beliefs, and identity may be different to that of the person you are caring for. If they are happy to talk to you about this, you should try to understand their beliefs, customs, needs and rituals around dying and death. In this way, you can ensure that their cultural values are respected, and you can plan for appropriate care. If they are not able talk to you about this, you could check if they have left instructions about the care they would want with their family, friends or those close to them.

In some cultures, it is traditional to have a high number of visitors, family, friends or members of the community to show respect and say a final farewell. You may need to be prepared for this and set up a rota with the family or those close to the person. You need to know what is important to the person you are caring for.



Part 2

Caring for the person at home – support and practical guidance

People who can support you as a carer

We introduced you to the Primary Care Team and the Community Palliative Care Team earlier in this booklet. Now let's look in more detail at how the healthcare professionals in these teams can help or support you.

If the person you are caring for is being discharged from hospital for palliative and end-of-life care, the hospital team will have referred you to the medical teams and healthcare professionals in the community who can support you at home.

If you are unsure about how to prepare yourself and your home, some of these professionals can give you clear information, support and direction.

Below are the key people who can support and assist you in caring for the person at home.

General Practitioner or GP (doctor), the GP will:

- advise you on managing pain and other common symptoms at the end of life
- refer the person to the Community Palliative Care Team when the time is right
- refer you to the Public Health Nurse who can help you to get in touch with other healthcare professionals and to source the equipment and resources needed

Make sure to keep in touch with the GP as the person nears the end of their life. The GP usually provides the death certificate after the person dies, as they are involved in their care and usually see them within 28 days of their death. If this is not the case, they may be unable to provide a death certificate. You can read more about this on page 36.

Your GP and Public Health Nurse are your most important healthcare resources to support you with the care needs of the person who is dying at home.

Check the hours your GP is available and who you can contact outside those hours. You need to know what to do and who to call when you are caring for the person at night or weekends when your GP practice is closed.



Remember if there is an emergency, dial 112 or 999.

GP Practice Nurse: General Practice Nurses work in the General Practice to provide nursing care for the practice. This includes screening services, immunisation services, health promotion and other care.

Public Health Nurses (PHNs) and Community Registered General Nurses (RGNs): These nurses can support you by providing general or nursing care to the person. This includes physical, emotional, psychological and spiritual care.

They can also support you in other ways. For example, they can:

- assess or check the person after they have been discharged from hospital and link in with or manage other services and supports such as the GP, home support, and help to access equipment and appliances
- give you advice on topics like managing medicine, nutrition, skincare, hygiene, safety, bowel management, and so on
- advocate for the person and their family, which means that they can be the one to talk up and request to get access to resources and services if they are needed

Other healthcare professionals will also provide care, and this care will depend on the person's specific needs. These professionals may include:

Occupational Therapists: Occupational Therapists (OTs) help people to have as much independence and quality of life as possible. OTs work with people in their own homes and in clinics based in primary care centres.

OTs provide advice and support on:

- preventing falls and pressure sores
- daily activities
- home adaptations and recommend equipment if needed

They also carry out assessments for care, sitting comfortably and using wheelchairs.

Physiotherapists: Community physiotherapy services are provided by the Primary Care Team. They help people who have suffered an injury or illness to regain their health or mobility through exercise and movement. Physiotherapists can:

- offer support by designing exercise programmes which focus on building and maintaining flexibility, strength and function
- provide guidance and care about pain management, respiratory or chest care, and falls prevention

Speech and language therapists: Speech and language therapists see people in a variety of settings. They can assess, diagnose and treat people with life-limiting conditions for speech, or swallowing difficulties.

Dietitians: Dietitians are experts on diet and nutrition. They can help with the person's comfort and improve the quality of their life by providing nutritional assessment and advice to them and their families.

Social workers: Social workers can assess the needs of the person who is dying, and of their family, and caregivers. These needs can include:

- mental and physical illness
- relationship issues
- preparation or support for the changes that are happening or are going to happen, including bereavement support

Your social worker can advise and assist you on practical things such as how to get an Emergency Medical Card.

Healthcare assistants (HCAs): The role of the HCA is to support patient care. Healthcare assistants can help with personal care and assist with activities of daily living such as bathing, dressing and feeding.



Nurses for Night Care: These nurses provide nursing care for the person and practical support for you at home in the last days of life. The service is provided through the Irish Cancer Society's Night Nursing Service, which delivers this service to people who are dying of cancer. The Irish Hospice Foundation funds this service for people dying with illnesses other than cancer. Care is usually delivered between 11pm and 7am.

Person-centred care

Providing person-centred care means that, where possible, you should try to meet the person's specific needs or do things in the way they would like. The person may have already shared their preferences for how they like to be cared for, but if not, you can ask them what their preferences are.

For example, they might have specific wishes about:

- how their hair is groomed
- wearing make-up
- favourite clothes to wear
- a favourite blanket
- what radio station or music to play
- what scent is used in the room

Being with a person who is dying at home:

- make sure to take time to simply sit with the person you are caring for and listen to them. Careful listening helps the person who is dying share their feelings if they want to. It may also help you understand their concerns
- be respectful of what the person says. Try not to brush them off or change the subject
- most people just want to be listened to as they talk about their hopes and fears. They may also just want to know they are not alone



If they can still use technology, do give the person a phone or handheld computer to allow them to stay in contact with friends and family, and to use the internet and social media. Even if they can't respond, they may enjoy seeing or hearing people who contact them.

Personal care

Caring for a person at end of life can often be a lovely and respectful opportunity to provide personal care for them. The person may still be able to care for themselves but need assistance. Be guided by them and help them as needed. Learning to provide care for them may be a gradual process as you get to know what they do and do not like. Always talk to the primary care team if you have any concerns or worries about how to provide personal care.

By personal care, we mean helping the person:

- wash
- change their clothes
- with their skincare
- with their mouthcare
- with nail care
- helping them in the bathroom

If you feel uncomfortable with giving this sort of care, you can ask the nurse or carer to help you. We talk about each of these ways of caring for a person below.

The Primary Care Team can guide and support you with the personal care that the person you are caring for will need. You should discuss all elements of their personal care with the medical team, and make sure you understand what you need to do. This will mean you can provide this care safely and without causing problems for you or the person you are caring for. Check that the person you are caring for is happy for you to provide personal care.

The Public Health Nurse or Community Registered General Nurse can also give you information and practical support to help you provide personal care. For example, the Public Health Nurse may arrange Home Support Services (a care package), which is a set of specific support services to meet the person's needs. This can include some Home Care hours for the person. This means you may have carers coming at set times to help you.

Here is some more detail on how you might help the person with their personal care needs.

Remember: Be guided by the person's Primary Care Team if you are providing personal care.

Washing and skincare: When someone can shower or bathe alone, you should respect their independence while also making sure they are safe. Let them know that you are there to support them.

If you need to help them, first make sure you have everything they need within easy reach. This includes items like soap, shampoo and shower gel. If the person needs a shower chair, make sure that that is ready for them too. Have towels within easy reach also, preferably a large towel to wrap around the person after their shower or bath and a small one for their head and feet. Keep the room warm and draught free. Make sure a change of clothes is close by to help with dressing. Keep mobility aids close by as well for ease of movement and safety.



If the person is unable to get out of bed, you can help them to have a wash in their bed. You will need a basin or bowl for washing. There are cleaning sprays you can use instead of soap that are easy to rinse away. Your Public Health Nurse can give you these. The nurse or carer can also guide you on how to wash the person and advise on what to use to moisturise their hands and feet regularly to prevent dryness.

Nail care: Nail care helps maintain their comfort and hygiene. If their nails are too difficult to manage or if you have concerns, ask for help from a healthcare professional.

Comfort care: As someone nears the end of life, their body may become less able to move easily due to their deteriorating condition. Everyday tasks such as sitting up, getting out of bed or walking around can become harder and may require more energy. At this point the person may be likely to spend most of their time in bed.

A member of the Primary Care Team may recommend and organise a hospital bed (also called a profile bed) which is generally a single bed. Because a hospital bed can be moved into different positions, it is easier to sit the person up or raise the bed to do things like washing, skincare and mouthcare. They may also recommend and organise an air mattress to protect the pressure points of the body from getting sore, so that the person will not need to be moved too often.

Sometimes, healthcare professionals might suggest using a hoist to move the person safely in and out of bed. This helps protect both the person receiving care and you or the healthcare staff. If you have any questions or concerns, your nurses and Primary Care team can answer them for you.

Incontinence

As a person who is dying becomes weaker, they might not be able to walk as far as the toilet. At first, you could talk with them, with the support of the healthcare team, about having a commode near the bed to make things easier.

If they can't get out of bed anymore, talk to your Primary Care Team. They can help guide you through these changes and suggest ways to keep the person comfortable. They can provide pads, gloves and barrier creams to prevent soreness and will show you the best ways to put on incontinence wear as the person may have urine and bowel incontinence.

They give you guidance to help with the personal hygiene of the person you are caring for and how best to dispose of incontinence wear.

The nurse or doctor might at some stage suggest using a catheter. This is a small tube which the doctor or nurse inserts into the person's bladder to drain urine into a catheter bag. There is no smell from the bag because the urine is sealed inside.

Catheter care:
The nurse will talk with you about catheter care:

- the GP or Public Health Nurse inserts the catheter and connects the catheter bag
- the catheter bag should be placed at the side of the bed below the level of the person's waist and it can be covered with a pillowcase or towel to make it more discreet and protect the person's dignity
- the nurse will show you how to empty the bag. You will need a container, like an old jug, to empty the catheter bag

Emotional care

Talking about feelings

The time approaching death is an emotional time. 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 these emotions, some of them, or none of them.

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

Listening to the person

Sitting with the person and listening is very 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 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, 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 worried 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 they may want to be reassured about what is happening and know 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.

Feeling grief before the person dies

People often assume that grief only happens after someone they care about has died. However, we now know that some people have feelings of grief before the death. This is called 'anticipatory grief' because it can happen when we are anticipating (expecting) a loved one to die, and it can be hard for us to make sense of this. We may even feel guilty or feel we are betraying the relationship by feeling this way when the person is still alive.

There are different ways to cope with grief before a person dies. You can:

- allow yourself to experience your feelings and reactions, and recognise them as grief
- talk to those you trust about what you are experiencing
- Spend time with the person you are caring for, listen to them and especially listen to any worries or concerns they may have
- find out what you can from medical or other healthcare professionals about what the person you are caring for may experience and how they will change as their life-limiting condition progresses. Ask questions about any worries you have
- take advantage of any support available – hospitals, hospices or voluntary organisations may provide counselling or support groups

Remember: There is no 'right' or 'wrong' way to feel when facing a loss.



Part 3

Look after yourself

Plan ahead



Coping with the ever-changing needs of being a carer can be hard for both you and the person you are caring for. As their care needs grow, they might feel more dependent on you, and you might start doubting yourself or feeling angry and guilty. It is okay to have these feelings, but you should reach out for support when you need it.

You should plan for how caregiving may impact different parts of your life. This can help you get through the difficulties that many carers face.

If you can, talk to the person you are caring for; try to talk openly about your worries, fears and concerns. This can help you both to find answers and reduce any feelings of isolation. Having discussions about helping with personal care, medication management, and any changes that need to happen to the home may be very helpful and will help you to plan. The more organised your plan is, the more in control you and the person you are caring for can feel.

Be kind to yourself

Caring for someone at the end of their life can be rewarding, but it can also take its toll on your physical and emotional wellbeing. You need to take the time to check in with yourself and take care of your own physical, emotional and spiritual needs. Here are some practical tips that may help you during your time as a carer.

Take breaks

Looking after someone at the end of life can be overwhelming and tiring. Taking a short break, even just for a little while, can really help both you and the person you are looking after. It gives you a chance to rest and gather your energy, so that you can handle any challenges better.

Remember to take care of yourself. Make sure you eat and drink enough to keep your body going. Caring is hard work, and your body needs fuel to keep up with it all. Keep yourself topped up with nutritious food and drink.

Look after your mental health

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. Take some quiet moments to relax or try doing some deep breathing exercises throughout the day to help you to stay calm when things get tough.

Keep active

Find some time to do something active that you enjoy such as walking, running, swimming, dancing, cycling or gardening. Caring for someone can be demanding both physically and mentally.

Accept support from family and friends

Family and friends may be able to step in to help you from time to time, even if it's just to let you take a short break for a walk, or to have a rest. They could also help by doing some shopping for you, for example, or helping with childcare. Think about who can help you with day-to-day duties and how you can stay in touch with them and let them know your needs. **Don't be afraid to accept help when offered.**

Get in touch with support groups

Support groups allow carers to come together and share their experiences and knowledge in a peer-to-peer, safe and non-judgemental space. You will find more information on carer support groups in the Resources section at the back of this booklet (page 42).

Try special interest and activity groups

Think about trying something new or something you love that gives you the chance to step back from caring. There are lots of special interest hobby groups and classes taking place across our local communities in things like sports, fitness, arts, creativity, hiking, or nature – whatever you are interested in. If it is easier for you to meet online, you will find activities and special interest groups that meet online. You can read more about these in our Resources section at the back of this booklet (page 42).

Summary of self-care tips

- Be kind, caring and compassionate with yourself
- Allow yourself to do what you need to do to look after yourself
- Supporting people to die well is a big challenge. Remember that when helping yourself to get through it, it is often the small things that count the most. That's where you can make a difference
- Seek help from others when you need it, and accept help when it is offered



Part 4

Caring for a person when they are dying

Personal care as a person nears the end of their life

A person's care needs will change as they are coming close to death. Many of the healthcare professionals who have been supporting you can guide you at this time. It is helpful to discuss this with them ahead of time, so that you know what to expect.

Eating and drinking: As someone nears the end of life, they often lose their appetite and may not eat for days before they die. If they are less aware of what's happening around them and sleeping a lot, you must be very careful when offering even a little bit of food or drink. Their ability to swallow may be very weak, so fluids can trickle into their windpipe and cause coughing. Make sure they are as upright as possible when eating or drinking and **always follow the healthcare team's instructions.**

When a person stops eating, they are not 'starving' from lack of food. A dying person does not need the energy food provides as they are not active. A person can survive for many days without food or fluids, and it does not cause them any distress or discomfort. The section on mouth care below will help you to make sure the person stays as hydrated and comfortable as possible.

Mouthcare: When a person is starting to lose consciousness, their lips and mouth can get dry. Healthcare professionals on the primary or palliative care team may show you how you can help the person's comfort. The Public Health Nurse may provide you with a mouthcare pack, which contains small sponges and can show you how to moisten a sponge in water and gently wet the persons mouth and lips. To make sure the sponge is not dripping wet, squeeze it against the side of a glass. Gently place the swab into the person's mouth. The person may suck on it, allowing you to rub the sponge around their tongue. Continue this for as long as they seem comfortable. Some people will close their mouth if they dislike the swabs, so you can just keep their lips moistened and leave them for a while before trying again.

If the person's mouth is open for a long time, their tongue can get very dry, and your nurse may recommend mouth moistening gels. You can also apply lip balm to their lips as their lips can also get very dry.

Managing the person's pain

Irish Hospice Foundation researched how people with a life-limiting illness can be helped to die well at home. The people who took part in the study described a good death as one that was comfortable, calm, and free from pain and suffering.

Our Dying Well at Home report **(https://hospicefoundation.ie/wp-content/uploads/2023/09/Dying-Well-at-Home-Report-Irish-Hospice-Foundation.pdf)** said that pain was one of the things that people fear most when nearing the end of their lives. We found that for both the people who were receiving care and the people who were providing care that keeping the person's pain well controlled was their top wish.

While not everyone experiences pain, when you are caring for someone at the end of life, you should know the difference between soreness and pain. This can help you provide the right level of comfort and support to the person.

Soreness: Soreness usually refers to a mild discomfort or tenderness in muscles or joints. It can be caused by several things, such as the person not changing position for a long time, pressure sores, or even just the natural effects of growing old. Soreness often improves with a gentle massage, helping the person change their position, applying heat or cold packs if the healthcare team feel this is appropriate.

The person's GP can prescribe pain relief for mild pain. Otherwise, a pharmacist can advise on safe medications that you can buy. Always talk to the healthcare team about this **before** you buy any pain relief so that they can advise and support you.

Pain: Depending on their medical condition, the person you are caring for may have little or no pain and may be kept comfortable by changing their position in the bed or turning the pillows.

However, if they are experiencing distress, discuss this with their medical team. They will do all they can do to make the person comfortable.

If the pain is more severe, the Community Palliative Care Team may be asked for their advice. They can assess and plan for pain management and they may connect the person to a **syringe driver** which is a lightweight battery-operated pump with a syringe. The syringe contains medication which is used to treat a person's symptoms. The pump allows the medication to be delivered at a regular rate over 24 hours. The team will explain the reasons for the pump and tell you about what to do

if the alarm sounds and who to contact. They can also link in with the GP and the community pharmacy about any medication that the person needs. Sometimes the pharmacists can deliver the medication to the person's home.

There are different medications that are used to manage symptoms in end-of-life care. If you have concerns about any medication the person is taking, talk the person's GP, nurse or pharmacist.

Sleep support

As the person is nearing the end of their life, they may sleep a lot, which may affect the natural day-night rhythm. They might be more awake at night when you are feeling tired.

If they have visitors during the day, it's okay to gently wake them up to help keep a routine going. Keeping them sitting up in bed for longer and doing activities like watching TV, listening to music, podcasts, or enjoying stories can help keep their mind active during the day. It will also make it more likely that they will be tired at night.

Sometimes the person can become restless and may make repeated movements, such as pulling at their blankets or clothes. This is usually because of physical changes in the body. You can remind the person gently about reality and reassure them they are safe, and you are with them.

If the person has memory problems or confusion, they may need medication for this, and the primary or palliative care team can help with this.



In the final days, it is common for someone to become unresponsive, and they may not wake up when you talk to them. Let the person relax and rest.

Remember: Hearing does not always fade before death, so even when the person seems less conscious, they may be able to hear you. Do still talk to them though, because your familiar voice is calming and provides reassurance.

When death is near – signs that the person is dying

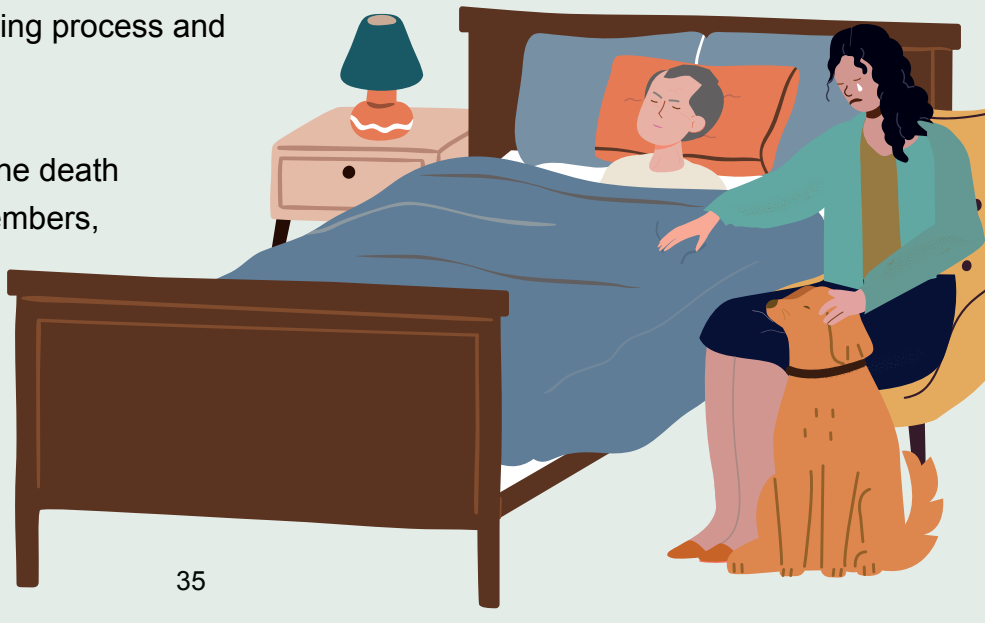
In their final days, the person will spend more time in bed and will sleep for longer periods. The periods of wakefulness will be less and they will sleep for longer until such a time when they do not respond when you talk to them.

When they are very near to death, there may be long gaps in a person's breathing. You can 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 the person, although it may be upsetting for you to listen to. This type of breathing does not mean the person is in pain.

In the days before death, the person might get agitated and appear restless. If this happens the primary care or palliative care team can advise you about what to do. They might suggest medication to help the person relax. It is normal for a person who is dying to have slight jerking movements when they are unconscious. This is just their body slowing down naturally.

Right before death, their skin colour will become very pale, and their fingers and toes may become bluish purple. Their hands will feel cold, and their breathing will become very light with long pauses or deep breaths. This is a normal part of the dying process and nothing to be afraid of.

It is very difficult to tell when the death will happen. Having family members, friends or neighbours around at this time may be helpful for you for support, as it can feel lonely.



Part 5

What happens after the person has died?

Care after death

When the person dies, it is important to continue to care for their body with dignity and respect, making sure that their religious, spiritual and cultural practices are followed.

Be sensitive and respectful of the needs of other people who are close to the person, and they may wish to support you with providing care after the person has died.

When the person dies, you will need to call their doctor so that they can officially confirm and certify the death. If it is night-time, you can contact the out of hours service and explain that the person has died, and that it was an expected death. A doctor will have to visit and formally pronounce that death has occurred, and if it is an on-call or a locum doctor, the person's GP should then be contacted the following morning.

Undertaker (Funeral Director): When death is confirmed, you can call your undertaker to plan arrangements (see resources on page 42). Most undertakers have a 24-hour contact number, but if it's very early in the morning, it is okay to wait until later. Just keep the room cool, leave a window open if it is safe to do so and turn the heat off in the room.

Family, friends or members of the community may call by to show respect and say a final farewell.

Personal care after death will usually include washing, positioning and dressing the person's body.

However, this is not the case for every death, and is related to religious practice, so you will need to check and seek support from those who know what the person would want, or check with their designated person.

After the person has died, there may be a nurse or a carer with you, who can help you to care for the person's body. If this is not the case, there are some practical things you can do, if it's culturally appropriate, while waiting for support from the undertaker, GP or other.

Practical things you can do while waiting for the undertaker

- after the person has died, and you are comfortable to do so, lay the person flat on their back and if possible, straighten their legs as they will start to get stiff. You could leave one pillow under the head as this helps to keep the mouth closed
- if the person has dentures, you can place them in their mouth, or ask for help from a nurse or doctor if you're unsure - as they give the face a more natural appearance
- fold a small towel under their chin to help keep their mouth closed, until the undertaker comes
- if they have a catheter (tube) in place, the nurse or care assistant or undertaker will remove this, but you can empty the bag if you want and lay it in the bed, so it is out of view when people come to pay their respects
- if they are wearing incontinence wear you can also leave this in place
- if the person has a syringe drive with medication, you can take out the batteries to stop the machine working but leave the tube in place for the medical team to remove
- keep the room cool. Turn off the heat in the room and leave a window open if it is safe to do so

You may like to stay with the person, or if there are family, relations or friends present, you might like to stay together or take turns to be alone with the person.

Death certificate: When the person dies, you will need to call their doctor so that they can officially confirm the death. If it is night-time, you can contact the doctor-on-call service and explain that the person has died, and that it was expected. A doctor will have to formally pronounce that death has occurred. If the doctor is an on-call or a locum doctor, contact the person's GP the following morning.

When death is confirmed, you can call your undertaker to plan arrangements.

Funeral preparations



You may have spoken with the person you were caring for about their funeral wishes and will be making sure that their religious practices are considered, but if not, you could check this with their family, friends or their GP and see who has the authority to make the decisions.

If you have not selected an undertaker or do not know of one in your area, a list is available on the Irish Association of Funeral Directors website **https://www.iafd.ie**

If you have an undertaker selected when you call them, they will check to see if the GP has pronounced the death and signed the death certificate. If the person wanted to be cremated, there is additional paperwork to complete.

Planning a funeral can be an emotional and expensive time, but the undertakers will help you. They will explain the funeral arrangements, including transport and preparation of the body and death notification (how to let people know the person has died). Your funeral director can help you to place a notice on **rip.ie**. Funeral services can be different depending on your preferences, religion and culture, and you can discuss this with the undertaker. The undertaker can also advise you on how to go about registering the death.

Financial support: If you need financial support for funeral costs, you may be eligible for an **Additional Needs Payment.**
https://www.citizensinformation.ie/en/social-welfare/supplementary-welfare-schemes/additional-needs-payment/

For more information on the Additional Needs Payment, visit the Citizens Information website under “Supplementary Welfare Schemes” or follow this link:
www.citizensinformation.ie/en/social-welfare/supplementary-welfare-schemes/additional-needs-payment/

Bereavement support



Grief is a normal part of experiencing a loss. Everyone grieves differently, but most people process their grief with the love and support of family, friends, colleagues and neighbours.

You can also freephone the Bereavement Support Line **1800 807 077** for emotional support and comfort.

There is no specific timeline for the grieving process. For some people, the second year can feel even harder as the reality sets in. If you find that you are struggling, speak to your GP and check out the resources section at the back of this booklet for additional support (page 42).

Children's grief

We should all remember that children grieve too. For more information on explaining death to a child and on supporting them as they grieve, see The Irish Childhood Bereavement Network resources, **www.childhoodbereavement.ie**. These are in the Resources section at the back of this booklet (page 42).



The **Bereavement Support Line** is a national freephone service which is available to anyone who is bereaved.

For more information, visit Irish Hospice Foundation's website under "Our Supports and Services" or see **bereaved.ie**

Notes page for carers:

You can put important notes and contact numbers here.

Supporting organisations

This list is not exhaustive, but a selection of supports to help the carer providing care in the home.

They are listed under the following headings:

- **Support for carers and care recipients**
- **Life-limiting illness support**
- **End-of-life care support**
- **Support after death**
- **Bereavement support**



Support for carers and care recipients

Organisation	Website and Phone
Irish Hospice Foundation	https://hospicefoundation.ie/ 01 679 3188
■ eLearning on the LMS platform - to learn more about caring for someone at home at end of life	https://elearning.hospicefoundation.ie/
■ Information and Support Line - providing information and support around end-of-life care	Freephone 1800 60 70 66 Monday to Friday 9am to 1pm
■ Nurses for Night Care	https://hospicefoundation.ie/our-supports-services/healthcare-hub/nurses-for-night-care/
Family Carers Ireland: National Freephone Careline	01 679 3188 https://www.familycarers.ie/ 1800 24 07 24
Citizens Information: Care in your Community	https://www.citizensinformation.ie/en/ 0818 07 4000
Care Alliance Ireland: Guiding Support for Family Carers	https://www.carealliance.ie/ 01 874 7776
HSE Home Support Service	https://www.hse.ie/eng/home-support-services/ 01 240 8787
HSE Primary Care Adult Occupational Therapy Service	https://www.hse.ie/eng/services/list/2/primarycare/ 01 240 8787
HSE Support and Services For Caring for Older People	https://www2.hse.ie/services/ 01 240 8787
Government Carer's Support Grant	https://www.citizensinformation.ie/en/social-welfare/carers/carers-support-grant/ 043 334 0000

Support for carers and care recipients (continued)

Organisation	Website and Phone
HSE Drugs Payment Scheme Card	https://www2.hse.ie/services/schemes-allowances/drugs-payment-scheme/card/ 1800 700 700
Sage Advocacy National Advocacy Service for Older People	https://sageadvocacy.ie/
Citizens Information Health Services for Older People	https://www.citizensinformation.ie/en/health/health-services/health-services-for-older-people/ 0818 07 4000
Citizens Information Entitlement to Health Services	https://www.citizensinformation.ie/en/health/health-system/entitlement-to-public-health-services/ 0818 07 4000
Senior Line Confidential listening service for older people	https://www.thirdageireland.ie/seniorline/contact 1800 80 45 91
Age and Opportunity Arts Resources	https://ageandopportunity.ie/#desktop 01 268 8607
National Medical Card Unit	https://www2.hse.ie/services/schemes-allowances/medical-cards/about-the-medical-card/contact/ 0818 22 44 78 (LoCall) or email: clientregistration@hse.ie
LGBTQ+ Ireland Support for Older Persons	https://lgbt.ie/get-information/older-lgbt-people/ 1800 929 539

Life-limiting illness support

Organisation	Website and Phone
Alzheimer's Society of Ireland: National Helpline Service	https://alzheimer.ie/ 1800 341 341
Dementia Understand Together: Freephone helpline	https://www.understandtogether.ie/ 1800 341 341
Irish Cancer Society	https://www.cancer.ie/ 1800 200 700
Irish Heart Foundation Carer Services	https://irishheart.ie/ 01 668 5001
COPD Ireland	https://copd.ie/ 01 5392181
Neurological Alliance Ireland	https://www.nai.ie/ 086 1216 957
Irish Kidney Association	https://ika.ie/ 053 1620 5306

Support after death

Organisation	Website and Phone
RIP.ie Practical Guide to Funeral Preparations	www.rip.ie
Citizens Information When Someone Dies	https://www.citizensinformation.ie/en/death/ when-someone-dies-in-ireland/ 0818 07 4000

Bereavement support

Organisation	Website and Phone
Irish Hospice Foundation Bereavement Support Line	www.bereaved.ie Freephone 1800 80 70 77 Available 10am to 1pm Monday to Friday
Irish Hospice Foundation Irish Childhood Bereavement Network	https://www.childhoodbereavement.ie/ 01 679 3188



Irish Hospice Foundation

Information and Support Line

End-of-Life Care | Advance Care Planning | Palliative Care

1800 60 70 66

Mon - Fri | 9am - 1pm



Providing information and support around end-of-life care

Freephone

1800 60 70 66

Monday - Friday
9am - 1pm

Information and Support:
support@hospicefoundation.ie

This service is for information purposes and is not intended to deliver clinical advice or assessment or crisis intervention.

Irish Hospice Foundation

Irish Hospice Foundation
Morrison Chambers,
32 Nassau Street,
Dublin 2,
D02 X627

hospicefoundation.ie
info@hospicefoundation.ie

Registered Charity Number 20013554

pobal
government supporting communities

The Hospital Saturday Fund

Plain English
Approved by NALA

Scan the QR code
to find out more about
when someone you care
about is dying at home.

