



# Toolkit

## for Compassionate End-of-Life Care

2nd Edition, updated 2024



**Irish  
Hospice  
Foundation**

To die and grieve well wherever the place



# Contents

Introduction.....	3
-------------------	---

1. Dying in Ireland .....	4
Helpful definitions .....	5

2. Communication.....	7
Getting the basics right.....	7
Communicating through personal protective equipment (PPE) .....	10
Breaking bad news .....	11
Breaking bad news over the phone.....	13
Breaking bad news that a person has died .....	15
Breaking bad news that a person has died over the phone .....	17
Giving bad news to children .....	18
Answering difficult questions.....	18
Dealing with conflict .....	20
Offering condolences and words of comfort .....	21

3. End-of-Life Care Planning and Preparation.....	22
Advance care planning .....	22
Advance Healthcare Directives.....	24

4. Care of the Dying Person.....	26
Recognising when death is imminent .....	26
The final hours: when dying is imminent.....	27
Spiritual care at the end of life .....	28
Caring for a person who is dying.....	28
Considerations for infection control.....	30
Supporting family and friends when a person is dying .....	32
Facilitating family meetings .....	34
Supporting families: additional considerations related to infectious diseases.....	34

5. Care After Death .....	36
Care of the body after death .....	36
End-of-life care ceremonial resources.....	37
Providing care for those who are grieving for a person who has died .....	37
Post-mortem examinations.....	39

6. Caring for Staff .....	41
Self-care in end-of-life care .....	41
Team care.....	42
Suggestions for self-care.....	43

7. Useful Resources and Websites .....	44
--	----

# Introduction

## End-of-life care is everyone's business

This is the **second edition** of the **Toolkit for Compassionate End-of-Life Care**, which has been produced, amended and updated by Irish Hospice Foundation (IHF). We are a national charity that addresses dying, death and bereavement in Ireland, whether a death occurs in hospital, a nursing home or other residential setting, a hospice or at home.

**Our aim in developing this toolkit is to provide healthcare workers with information, guidance, language and resources that will support them in caring for those who are dying and their family and friends.** We believe that end-of-life care is everyone's business, and we hope that all healthcare workers, regardless of setting, will find value in this toolkit appropriate to their role. It has been divided into clear sections so that the reader can dip into the section that is most relevant to them at a point in time.

We have tried to address issues that apply broadly to anticipated or expected deaths in adults, and have not focussed specifically on other deaths, such as death by suicide, sudden deaths, stillbirths, deaths in children and young people, or on other issues such as cultural considerations. Information on all of these and on many other issues around dying, death and bereavement is available on the IHF website: [www.hospicefoundation.ie](http://www.hospicefoundation.ie)

Medical management at end of life and other clinical or legal considerations are outside the scope of this publication, and guidance on these matters should be sought from appropriate colleagues and from other recognised sources who can offer expert advice and support.

We hope this toolkit will support healthcare workers in their everyday interactions with patients, residents and their family and friends as they provide a compassionate, person-centred approach to end-of-life care.

### Important Note:

Please note that this toolkit has been compiled by IHF to support those who are caring for patients and residents at end of life, and the views expressed are those of IHF. Neither IHF nor any person acting on its behalf can be held responsible for any use made on the information in this publication. It is not intended to replace medical or legal advice.

# 1.

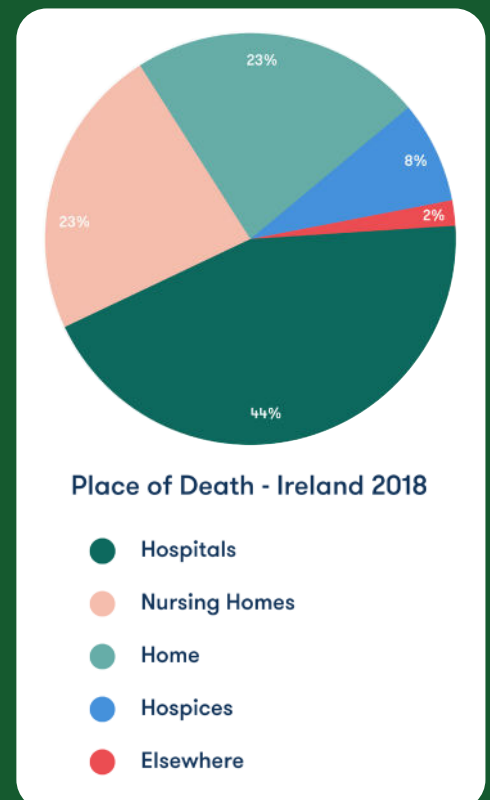
# Dying in Ireland

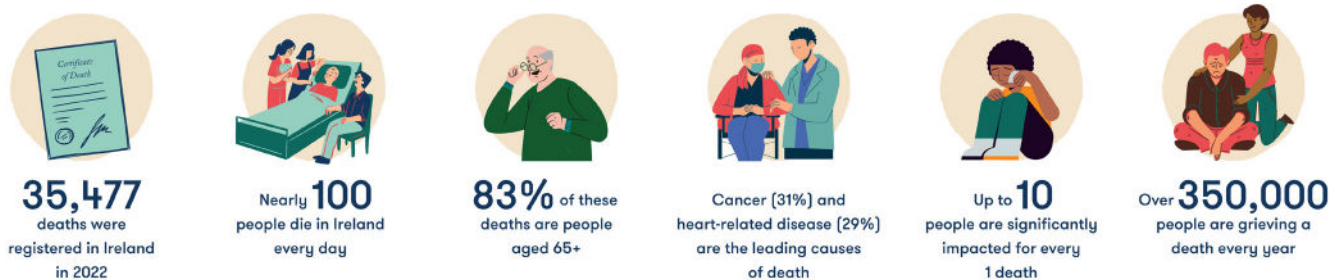
Every day in Ireland, approximately 100 people die, and up to 10 people are impacted by each death. That means around 1,000 people will be newly bereaved. Every death matters – and we only have one chance to get it right. IHF’s vision is an Ireland where people experiencing dying, death and bereavement are provided with the care and support they need. We want more people in Ireland to have a good death and we want appropriate information and support to be available to the bereaved.

The majority of deaths will occur in a healthcare setting, either an acute hospital or a long-term residential facility (see chart below using CSO figures from 2018).

For many years, IHF has worked in collaboration with the HSE and other care agencies to promote understanding, information and awareness about what constitutes good end-of-life care.

The Hospice Friendly Hospitals (HFH) Programme is an initiative of the IHF in partnership with the HSE. It was established in 2007 to introduce a strategic and focused approach to the improvement of end-of-life care in acute hospitals. The HFH Programme aims to improve the experiences of patients and their families in acute hospitals and supports staff well-being. Adult, paediatric and maternity hospitals and units nationwide are engaged with the HFH programme and working to improve end-of-life care in their respective setting.





Dying Well at Home (DWAH) is a programme to support individuals who wish to die at home and for those caring for them. The programme aims to facilitate end-of-life care by collaborating with, supporting and working with patients, their families and the wide array of healthcare professionals who provide end-of-life and palliative care in the home. Nurses for Night Care, supported by the HSE, continues as part of DWAH, supporting people with non-malignant life-limiting conditions in their final days to die at home.

Caru is a quality improvement programme for nursing homes developed by IHF in partnership with the All Ireland Institute of Hospice & Palliative Care (AIHPC). It enables staff to deliver compassionate, person-centred end-of-life care to residents and their relatives and friends through a programme of training and development workshops, regional network events and ongoing supports. See [www.caru.ie](http://www.caru.ie) for details.

More information on IHF healthcare programmes can be found on [www.hospicefoundation.ie](http://www.hospicefoundation.ie)

## Helpful definitions

Here are some key terms and phrases you will come across throughout this toolkit. Terms are presented in alphabetical order and are defined as we understand and use them in IHF.

- **Bereavement care** – Support, information and services available to bereaved people through their families, friends, communities, workplaces, healthcare providers and education systems, regardless of the circumstances of their loss.
- **End-of-life care/Care at end of life** – We use these terms to refer to all aspects of the care relating to dying, death and bereavement provided towards the end of life. In this context, ‘end of life’ can be from the moment someone receives a life-limiting diagnosis, through the months before death, up to and including the final hours – a continuum rather than a point in time. We use ‘end-of-life care’ to refer to the care of people with advanced life-limiting conditions, for whom death within one to two years is likely, as well as those in the terminal phase of illness. It also encompasses care of the remains of the deceased person.
- **Life-limiting illness/condition** – A condition or illness from which there is no reasonable hope of cure and from which a person is expected to die.
- **Palliative care** – Palliative care is a term for the type of care provided to people with life-limiting conditions by hospices and in many other care settings. It is the term most commonly used by people working in medical or healthcare settings.

The statistics in the graphic at the top of this page are from the following sources:

- [Vital Statistics Yearly Summary 2022](#) - CSO - Central Statistics Office
- Matthews, S., Pierce, M., Hurley, E., O'Brien Green, S., Johnston, B.M., Normand, C. and May, P. (2021) *Dying and death in Ireland: What do we routinely measure and how can we improve?* Dublin: Irish Hospice Foundation.
- Ashton M. Verdery, Emily Smith-Greenway, Rachel Margolis, and Jonathan Daw (2020), *Tracking the reach of COVID-19 kin loss with a bereavement multiplier applied to the United States*, <https://www.pnas.org/doi/full/10.1073/pnas.2007476117>

The palliative approach focuses on the prevention and relief of suffering by means of assessing and treating pain and other physical, psychological or spiritual problems. The aim of palliative care is to enhance quality of life and wherever possible to positively influence the needs of illness. Many people mistakenly believe that you can only receive palliative care when other treatments are no longer possible. Palliative care can be provided to people of any age and at any stage of their illness.

The *Adult Palliative Care Services: Model of Care for Ireland (The National Clinical Programme for Palliative Care, 2019)* sets out how the provision of palliative care is structured in three levels:

## Level One:

### Palliative care approach:

- Palliative care principles should be practiced by all healthcare professionals. The palliative care approach should be a core skill of every clinician at hospital and community level. Many patients with a progressive and advanced disease will have their care needs met comprehensively and satisfactorily without referral to specialist palliative care units or personnel.

## Level Two:

### General palliative care:

- At an intermediate level, a proportion of patients and families will benefit from the expertise of healthcare professionals who, although not engaged full time in palliative care, have had some additional training and experience in palliative care, perhaps to diploma level. Such intermediate level expertise may be available in hospital or community settings.

## Level Three:

### Specialist palliative care:

- Specialist palliative care services are those services whose core activity is focused to the provision of palliative care. These services are involved in the care of patients with more complex and challenging care needs, and consequently, require a greater degree of training, staff and other resources. Specialist palliative care services, because of the nature of the needs they are designed to meet, are analogous to secondary or tertiary healthcare services.

This toolkit aims to support healthcare staff to provide a **Level 1 - Palliative care approach**.

## Palliative Care Booklet

“Palliative Care: What is it and who is it for” by Irish Hospice Foundation is a useful resource for you, your patients and the people close to them, answering frequently asked questions on palliative care. Scan the QR code to download a copy.



# 2.

# Communication

## Getting the basics right

When we communicate with another person, we make our impact through:

- Non-verbal communication (sometimes called our body language) – how we dress, how we stand or sit, our eye contact, hand gestures, facial expressions;
- Tone of voice, our accent, pitch and volume; and
- The words we use.



Knowing how we make our impact can help us to be more effective communicators.

## Tips for impactful communication

### Non-verbal

- Always have your name badge where it can be seen.
- Be appropriately groomed - look clean, tidy and professional.
- Where possible, make eye contact throughout the conversation and have your eyes at the same level as the person you are talking with. Sometimes it is our own discomfort that prevents us from making appropriate eye contact. If this happens to you, you can stare at the space at the top of the nose between the eyes – this gives the person the sense that you are making eye contact, but may be more comfortable for you.



- Use open body language. Consider your proximity, balancing personal space and privacy. Mirroring the other person's body language (their seating position, posture, gestures and expressions) is a good way to show empathy, create a bond and enhance the connection. Use 'open' body language with open palms and unfolded arms and legs. If standing, come into the person's space; don't have a conversation from a doorway. Check the direction of your feet. Often we communicate to people with our heads turned one way but our feet facing in another direction. This gives the impression that you are not fully engaged with the person.
- Avoid having a desk or other object (e.g., a clipboard or notes) as a barrier.
- Use touch and gestures appropriately, again being aware of cultural sensitivities – take your cue from the person you are talking with.
- All of the above is even more important if you are wearing a face mask and personal protective equipment (PPE).

### Tone of voice

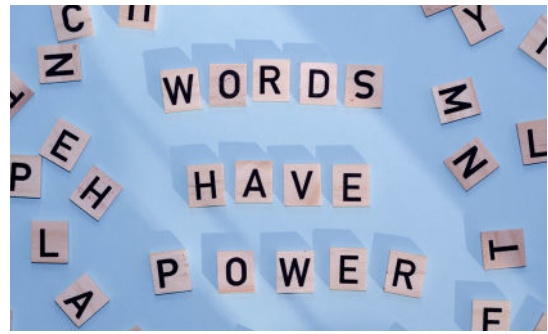
- Use your tone to convey the meaning of your message. When a situation calls for sincerity and empathy, be sincere.
- Have a welcoming gentle tone to enhance the sharing of information.
- You may need to raise your speaking volume if you are wearing a face mask. Speaking a little slower should help you to be heard better by the other person.

“People will forget what you said, people will forget what you did, but people will never forget how you made them feel.”

Maya Angelou

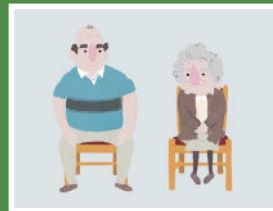
## Words

- The words we use are very important. An inappropriate phrase can alter or undermine your message.
- Avoid medical terminology and jargon.
- Avoid using euphemisms, which can lead to confusion. Use words like 'dying', 'died', 'dead'.
- If there is a mismatch between the words you use and the body language and tone of voice, then the words will lose their impact. The person will assign a meaning from the non-verbal communication and the tone of voice.



### Useful resource: Discussing Dying

The Discussing Dying short film has been developed by NHS Education for Scotland, with input from IHF, and aims to help healthcare professionals discuss dying openly and honestly with their patients.



## Communicate clearly and honestly

- Use simple language as this helps you get your message across.
- Check if the person needs assistance in understanding information/the words used.
- Consider age, cultural, cognitive and language abilities.
- Avoid jargon and euphemisms.
- Acknowledge difficult questions and respond appropriately based on your role.
- Think of creative ways to demonstrate your message (e.g., draw pictures, use photos, images or videos).
- Be comfortable with silence.
- Paraphrase information and check understanding.

## Sample phrases

- “ *What makes you ask that today?* ”
- “ *What is your biggest worry at the moment? Help me understand what would help or comfort you.* ”
- “ *I don't know, but I will try to find someone who can help.* ”
- “ *Would you like me to repeat that?* ”
- “ *What do you understand by that?* ”
- “ *I've given you a lot of information. Take some time to think about what we have spoken about, and we can chat again if you have further questions.* ”

## Communicating through personal protective equipment (PPE)

Following the impact of the COVID-19 Pandemic, patients/residents and their families have found themselves in a completely changed environment, where the need for strict infection prevention and control procedures can impact on the end-of-life care experience. This may lead to heightened feelings of upset and anger, abandonment and isolation, confusion, fear and a sense of being out of control. This is a difficult situation for anyone to be in. It is important to acknowledge those feelings and offer comfort and reassurance. Having clear communication channels to provide information and respond to queries is vital.

### Show the person who you are and make the human connection

In the interactions you have with patients/residents, relatives and friends, try not to let PPE become a social barrier. People in isolation may need to feel a connection with others even more.

- “Hello, my name is . . .”
- Place a photo of you and/or write your name on the outside of your PPE.

### Be a comforting presence

If you're wearing PPE, your body language, tone of voice and eye contact are even more important. Your smile and warmth can be conveyed through your eyes, even if you're wearing a face mask.

Move slowly if you can. Enter the person's room gently.

### Acknowledge emotions and feelings

Ask how the person is feeling. Provide information, reassurance, words of kindness. Focus on maintaining hope – think about what can be done and what can be done well.

- *‘I can help you contact your loved ones.’*
- *‘I can be here with you if you are frightened.’*
- *‘I can help to make you feel more comfortable.’*
- *‘I can help your mother to feel more comfortable.’*
- *‘I will take care of your father.’*
- *‘I am here for you.’*

## Breaking bad news

News is any information that seriously affects a person's view of their future.<sup>1</sup> It is the person receiving the news that decides if it is bad. As healthcare workers, we always need to be conscious that whenever we have to give a person information, for example, of a test result, a diagnosis, a change in condition. This may be perceived as bad news to that person. Think of breaking bad news as a process, not as a single event. It may take the person several conversations before they are able to grasp all that you are saying, especially if the information is complex.

Here are five recommended steps for breaking bad news:

### Step 1:

#### Prepare yourself

- Prepare, mentally and emotionally - think about yourself, the other person and the news itself.
- Set time aside. Find a quiet, private room where you can avoid interruptions. Leave your phone or pager with a colleague. Never give sensitive news in public places, such as corridors.
- Know the facts. Make sure you have the right person and the right results/news. Have options or treatment plans prepared to discuss with the person as appropriate.
- If you are unable to stay with the person while they process the news, make sure there is someone who can.

### Step 2:

#### Make a good connection

- Welcome them, tell them your name and your role, and ask them to take a seat. Sit down yourself and ensure your body language is open and engaging.
- Find out what the person already knows:
  - *"How were you feeling coming in here today?"*
  - *"How have you been since I saw you last?"*
  - *"What do you already know about your illness?"*
  - *"I haven't met you before today. Maybe we could start off with you telling me a bit about your illness and how you've come to be here today?"*
- Find out how much they want to know: *"I have your results—are you the sort of person who likes to know a lot or a little?"* Remember that they have a right to know and to NOT know.



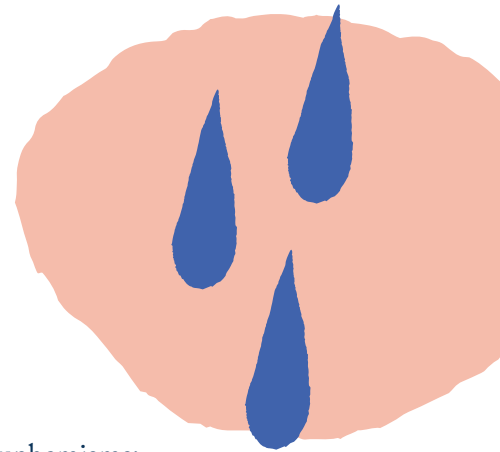
<sup>1</sup> Buckman R. (1992) How to Break Bad News: A Guide for Health Care Professionals. University of Toronto Press, Toronto

### Step 3:

Prepare them, and then **be gentle** as you deliver the news

Here are some example scenarios:

- Prepare them for what is coming next: *“I wish I had better news to give you today”, “I’m sorry, but the news isn’t as good as we’d hoped it might be”, “Unfortunately, I have some bad news for you”.*
- Pause. Allow the warning to land.
- Gently deliver the news using clear simple language and avoid jargon and euphemisms: *“The lump in your breast is cancer”.*
- If the news is complex, break it into small chunks. Then check that the person understands what you have said, for example: *“Can you tell me in your own words what you understand we’ve talked about?”*



### Step 4:

**Acknowledge** the shock

- Even if the news was anticipated, hearing the confirmation can be a shock. It is important to acknowledge the emotional impact of the news: *“I can see this news has come as a shock”, “I can see this is upsetting for you to hear”.*
- Give the person time; allow a silent pause.
- Deal with the person’s concerns before you deal with questions of detail: *“What is your biggest concern right now?”*

### Step 5:

**Plan** for the future

- Give a clear plan as to what will happen next. Depending on how the person responds to the news, it might be appropriate to discuss treatment options or it might be better to make a plan to discuss further options at another time. It is useful to have written information available to enforce your spoken message.
- The person affected by the news might be worried about how they are going to tell others. Offer to support them with this. Always make sure you have the person’s permission before giving information to others.
- Find out if there is anyone in particular the person would like to talk to, for example, a social worker, or pastoral care.
- Avoid phrases like “there’s nothing more we can do” - a better way is to say something like “There isn’t any specific treatment to make your illness go away, but there is a lot we can offer to help you to cope.”
- Provide the name and number of a support person they can call if they have further questions.
- Document the details of the discussion, using the same language used in the conversation, and the follow-up plan in as much detail as possible.

## Breaking bad news over the phone

**Ideally, bad news should be given in person.** However, there may be times when this is not possible, and you have to deliver the news over the phone. Think of breaking bad news as a process, not as a single event. It may take the person several conversations before they are able to grasp all that you are saying, especially if the information is complex.

**Here are some tips for breaking bad news over the phone:**



### Step 1: Prepare yourself

- Prepare, mentally and emotionally - think about yourself, the person receiving the news and the news itself.
- Set time aside. Find a quiet private room to call where you can avoid interruptions.
- Know the facts. Make sure you have the right person and the right results/news. Have options or treatment plans prepared to discuss with the person as appropriate.

### Step 2: Make a good connection

- Identify yourself. Tell them your name, your role and where you are calling from.
- Confirm whom you are speaking to.
- Ask the person if they are sitting down and if anyone else is there with them.<sup>2</sup>
- **If you are delivering news of a death, then go to Step 3.**
- Find out what the person already knows: *“How have you been since I saw you last?”*, *“What do you already know about your illness?”*, *“What do you know about how your mother/wife is doing at the moment?”*
- Find out how much they want to know: *“I have your results—are you the sort of person who likes to know a lot or a little?”* Remember that they have a right to know and to NOT know.

### Step 3: Prepare them, and then **be gentle** as you deliver the news

- Prepare them for what is coming next: *“I wish I had better news to give you today”, “I’m sorry, but the news isn’t as good as we’d hoped it might be”, “Unfortunately, I have some bad news for you”.*
- Pause. Allow the warning to land.
- Gently deliver the news using clear simple language and avoid jargon and euphemisms: *“The lump in your breast is cancer”.*
- If the news is complex, break it into small chunks and check that the person understands each chunk: *“Can you tell me in your own words what you understand we have talked about?”*

<sup>2</sup> Buckman R. (1992) How to Break Bad News: A Guide for Health Care Professionals. University of Toronto Press, Toronto

## Step 4:

### Acknowledge the shock

- Even if the news was anticipated, hearing the confirmation can be a shock. It is important to acknowledge the emotional impact of the news - *“It is understandable if this news comes as a shock.”*
- Give the person time; allow a silent pause.
- If there is another person with them, offer to speak to them. If they are alone ask them if there is anyone else they would like you to call.
- Deal with the person’s concerns before you deal with questions of detail: *“What is your biggest concern right now?”*

## Step 5:

### Plan for the future

- Give a clear plan as to what will happen next. Depending on the circumstances and on how the person responds to the news, it may be appropriate to discuss treatment options, though it is generally better to plan a discussion of further options at another time.
- Offer to meet relatives or others with the person. They might be worried about how they are going to tell others the news. Always make sure you have the person’s permission before giving information to others.
- Find out if there is anyone in particular the person would like to talk to, for example, a social worker, or pastoral care.
- Avoid phrases like “there’s nothing more we can do” - a better way is to say something like *“There isn’t any specific treatment to make your illness go away, but there is a lot we can offer to help you to cope.”*
- Provide the name and phone number of a support person they can call if they have further questions.
- Stay on the phone until the person indicates that they are ready to end the conversation.
- Document the details of the discussion, using the same language used in the conversation, and the follow-up plan in as much detail as possible.

## Breaking bad news that a person has died

The news of a death is difficult to give and even more difficult to hear. No one can ever prepare themselves to hear this news. Even if a death is expected, the news of the death will come as a shock, and how a person receives this news will likely stay with them forever.

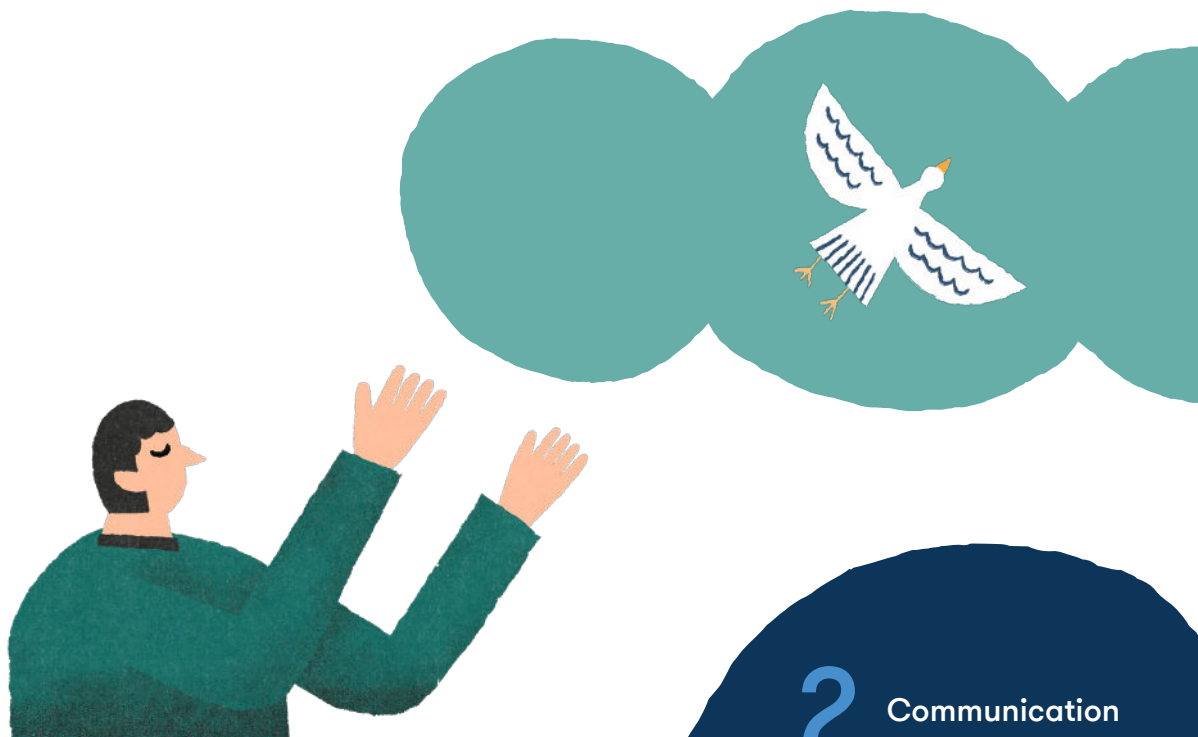
It is challenging to break the news that a person has died, but there are steps you can follow to help make the process easier.

### Fives steps for breaking bad news when a person has died:

#### Step 1:

#### Prepare yourself

- Prepare, mentally and emotionally - think about yourself, the other person and the news itself. It is important to be mindful of the issues that may arise within different death scenarios – for example, expected death, sudden death, the death of a child, miscarriage, intrauterine death, stillbirth, neonatal death. Prepare yourself as much as you can to be able to support relatives and friends with both the practical and the emotional aspects of a relative dying.
- Set time aside. Find a quiet private room where you can avoid interruptions. Never give bad news in public places, such as corridors.
- Know the facts. Make sure you have the right person and the right results/news.
- Arrange to have another member of staff with you, especially if you are unable to stay with the person while they process the news.
- Take a moment for yourself before you break the news, as well as checking your appearance. Pause and take some deep breaths.





## Step 2:

### Make a good **connection**

- Introduce yourself; tell them your name and your role.
- Ask them to take a seat. Sit down yourself and ensure your body language is open and calming and you maintain a good level of eye contact.
- Build on their current understanding – this will be dependent on the circumstances surrounding the death. *“Can you tell me what you understand about your mother’s condition?”*, *“Can you tell me what you have been told so far?”*
- Take your cue from their current knowledge about what information gaps you may need to fill.

## Step 3:

### Prepare them, and then **be gentle** as you deliver the news

- Prepare them for what is coming next: *“I wish I had better news to give you today”*, *“Unfortunately, I have some very bad news for you”*.
- Pause. Allow the information to land.
- Gently deliver the news using clear simple language and avoid jargon and euphemisms. *“Your mother has died”*.
- Use the words dead and died. While this may seem blunt, it avoids the confusion that euphemisms like ‘passed’ and ‘passed away’ might cause.

## Step 4:

### **Acknowledge** the shock

- Even if the news was anticipated, hearing the confirmation can be a shock. It is important to acknowledge the emotional impact of the news. - *“I can see this is a big shock for you”*.
- Give the person time; allow a silent pause.
- There is often a temptation to provide more information following the delivery of the bad news. However, in this situation it is important to allow time for the news to be absorbed.
- Encourage the expression of emotion that comes as a reaction to the news. Allow silent pauses.



## Step 5:

### Plan for the future

- Deal with the person's concerns before you deal with details.
- Give a clear plan as to what will happen next – including details about spending time with their loved one. Reassure their relatives and friends that they are not alone and that staff are there to support them.
- Find out if there is anyone in particular the person would like to talk to, for example, a social worker, or pastoral care.
- Provide the name and number of a support person they can call if they have further questions.
- Document the details of the discussion, using the same language used in the conversation, and the follow-up plan in as much detail as possible.

## Breaking bad news that a person has died over the phone

- Find a quiet room and mentally prepare before dialling. Pause and take some deep breaths.
- Identify yourself and confirm whom you are speaking to.
- Ask if there is anyone else with the person.
- Suggest that the person you are speaking with sits down.
- Prepare them and pause before breaking the news gently, using simple language. *"I'm afraid I have bad news"*.
- Acknowledge the shock.
- Take your cue from the person's response about what information gaps you may need to fill.
- Provide the contact name and direct line number for you/a colleague.
- Stay on the phone until the person indicates they are ready to end the conversation. Contact the hospital reception/security desk and inform that relatives and friends will be arriving and if possible arrange for parking near the entrance to the hospital.
- Document and liaise with the multidisciplinary team.
- Ensure a member of staff greets them on arrival at the hospital and ward or care centre.



## Giving bad news to children

It is very upsetting to know that a family member or friend will die. This can be a very difficult time for a child if they do not fully understand what is happening. It is painful to see a child upset, but children do cope better with sad news when they are told the truth. Clear, age-appropriate language is the best way to communicate the news. Parents and guardians may find it helpful to get support from a friend or relative when they are breaking bad news to their child. Visit Irish Childhood Bereavement Network for more information: [www.childhoodbereavement.ie](http://www.childhoodbereavement.ie)



## Answering difficult questions

Working in healthcare, especially when dealing with people who are at end of life, often requires us to respond to these types of questions. These questions are often asked at times we are not expecting them.

Answering difficult questions might make us feel uncomfortable, unsure about where the conversation is likely to lead and we may worry about ‘saying the wrong thing’. We often focus on keeping patients happy and comfortable and making them feel better. Sometimes we may respond with a jovial “you’re grand” or “don’t worry” or “not on my shift”.

**‘This medication isn’t doing me any good. I don’t think I am going to make it, do you?’**

When a person (patient or resident) is concerned about something and they want to talk about it, they will choose who they speak to, and they will make this choice based on who they feel will be the best person to have this conversation with. For the patient or resident, the best person is often a person whom they can trust, whom they feel will be most likely to listen to them and whom they feel will be empathetic. If the result is a closing down of the conversation, they might choose not to voice their concerns again.

As a staff member, it is important to recognise that if a patient or resident chooses to have a conversation with you about what is worrying them, then it is because they believe you will listen and help. Your job is to accept that trust and explore their concerns with them within your role or appropriate to your role. You don’t need to have the right answers; it is not about that. It is about allowing the person to express what it is they are worried about, listening to them and then providing them with the support they need. While seeking out those who might help further is one part of these conversations, for many the provision of a kind, listening ear is often what is most beneficial.

Whilst it is normal to feel uncomfortable when difficult questions are asked, it’s important not to panic and rush a response. Instead, gently probe to find out what lies behind the question:

*“What makes you ask that?”*

*“Are you worried about something?”*

*“Do you want to talk about what is worrying you?”*

*“How can I help?”*

## “Am I dying?”

This is a particularly difficult question to hear, listen to and answer. Using the responses listed above can help, but sometimes the person asking the question is looking for clarity. Maybe they have things they need to do, say or sort out, and are looking for an honest answer so they can plan for what is important to them. Often the person will have a sense that they are coming to the end of their life and are looking for another person to listen to them as they express this.

It is important to be gentle but honest with a patient. If you do not know what to say, you might say, ‘I don’t know, but I can find someone who can talk to you about what you’re feeling.’ If you are aware that they are dying, you might say: ‘You are sick enough to die,’ or ‘Your mother is sick enough to die.’ Ask them what they are feeling, worried about or what other questions they might have.

“Explaining to patient and/or family that the patient is ‘sick enough to die’ won’t make them sicker, but it will enable everyone to understand the gravity of the situation and to respond appropriately.”

*Talking about dying: How to begin honest conversations about what lies ahead.* Royal College of Physicians, UK 2018

### Tips for dealing with difficult questions:

- Take a deep breath and pause before you answer.
- Be genuine and compassionate.
- Respond appropriately based on your role.
- Give the person your full attention and listen to them - really listen.
- Allow the person to express their thoughts and feelings.
- Allow for silent pauses.
- Use open-ended questions to gently find out what is on the person’s mind.
- Be honest. It’s okay to say ‘I don’t know’ if you don’t.
- It might be appropriate to say you cannot answer the questions but you will try to find someone who can.
- Document the conversation and pass it to the relevant person.
- Ensure you follow up and update the person with any further information.
- Talk to a trusted colleague about how you feel.



## Dealing with conflict

End-of-life care is challenging work. When people are at their most vulnerable, raw emotions often come to the surface. Patients and those close to them may display anger towards you. Healthcare workers often have to manage these situations with sensitivity and compassion.

### Here are some tips for dealing with conflict:

- Each conflict situation has three elements – you, the other person (or people) and the situation. You only have control over one of these elements – YOU.
- You may have some knowledge of the situation, and you can use this knowledge to defuse things.
- You have absolutely no control over the other person. Telling them to calm down or not to worry is probably not going to work!
- Never lose your cool or become angry and upset. If you feel like this is going to happen, then withdraw from the situation. Seek support from a colleague who can intervene.
- You can use your communication skills, conversation tone and volume to try and defuse a conflict situation using the following approaches:
  - If they are shouting loudly, you speak assertively but with lower volume.
  - If they are speaking fast, you speak at a slower pace.
  - If they are waving their arms around gesturing vigorously, you have to display calm, open and non-threatening body language.
- Remember the heat of anger tends to flare passionately for only a short time. If you maintain your communication skills, you should be able to dampen the flames.
- It is important to first and foremost acknowledge the other person's feelings. *"I can see you are very angry", "I can see how upset you are"*.
- Find out the assumptions which the other person has made, to which they are reacting with their feelings. *"Can you tell me what you understand about..."*, *"Can you tell me what has happened"*.
- Only when you have acknowledged their feelings and found out their assumptions can you then begin to establish the facts and bring clarity to the situation.
- Once the anger has gone from the situation, you can help build rapport by matching the other person's communication and mirroring their body language. Mirroring the other person's body language (their seating position, posture, gestures and expressions) is a good way to show empathy, create a bond and enhance the connection.
- Never take anger as a personal attack on you; it is very unlikely that it is about you.
- There may be a legitimate reason for the anger. Make sure that your resolution involves addressing the root cause, whether this be in dealing with it directly yourself, or reporting it to the relevant person.

## Offering condolences and words of comfort

When a person has died, it is important that staff members acknowledge the death and offer their condolences to their relatives and friends. This may cause anxiety about what to say and how to say it, and worry about causing further upset to those who are grieving the death of a loved one.

### Here are some tips that might help:

- It is really important to **acknowledge** the loss: *“I am very sorry that your mother has died”*. *“Please accept my sincere condolences”*, *“You are in my thoughts”*.
- Remember, even though the death may have been expected, it can still come as a shock. *“Death is always a shock, even when it is expected”*.
- Offer **support**: *“I am here for you”*, *“Is there anything I can do to help you?”*, *“Is there anything that you need?”*, *“Would you like me to call someone (priest/faith leader/family member/friend)?”*.
- Remind them that there is no need to rush anything or make any decisions right now.
- It can help to talk about the person *“It has been an honour looking after your mother”*, *“I am going to miss her”*.
- Remember that the majority of the impact of our communication comes from our non-verbal messaging. Be present. Sometimes words are not necessary; just being there for another person can be enough.

### Things to avoid saying:

- *“I know how you feel”*. You can never know how another person feels.
- *“At least.....”*. (For example: *“At least the suffering is over”*, *“At least the pain has stopped”*). Saying ‘at least’ can diminish the gravity of the death for someone.
- *“They have gone to a better place”*, *“He/she is happy now”*, *“They had a good innings”*, *“He/she was a good age”*, *“You have an angel in heaven”*, *“He is gone/passed/expired”*, *“Things could be worse...”*

Most staff will not be delivering bad news about end of life. However, it is important for all staff to know how it can be delivered well because we can all have a supporting role to play. The animation below can offer some guidance on how to do this.

### Delivering Bad News

This short animation gives five steps to help you deliver bad news. It is suitable for health and social care professionals or first responders who may have to deliver bad news as part of their job.



## 3.

# End-of-Life Care Planning and Preparation

## Advance care planning

Advance care planning (ACP) is thinking about, talking about and telling others about one's personal values, wishes, decisions and preferences for their future care. Advance care planning is especially effective through meaningful conversations. It can be beneficial to write, voice record, or video record any advance care plans that a person makes. It is a way of helping a person to understand their illness or medical condition and how it might impact them in the future. It is also a way to find out what matters to the person and what their wishes and preferences are.

ACP discussions are an important aspect of person-centred care and are particularly important when a person has a life-limiting illness. ACP is not a once-off task; it is a series of conversations that consider a wide range of end-of-life matters, from place of care, to place of death, to making funeral arrangements.

Advance care planning is an ongoing process, but when decisions, preferences, wishes or values have been identified, it is helpful for a person to write them down or record them. This way, if they are unable to express themselves later, their will and preference is more likely to be followed.

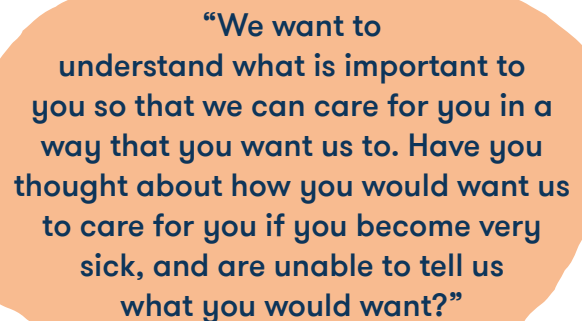
Advance care planning should be started as early as possible, ideally while a person is still very well. However, it is especially important if and when:

- The person has a life-limiting, progressive illness.
- The person's treatment preferences differ from the advice of their healthcare team.
- There is a significant deterioration in the person's condition.
- A treatment decision needs to be made.
- At the time of referring to Specialist Palliative Care services.
- You can answer 'no' to the surprise question *'Would you be surprised if this person dies within 12 months?'*

## Having an advance care planning conversation

Some people may not be ready or willing to have a conversation about their future care, and if this is the case, then you should respect their wishes not to. You can let them know that this is something that can be revisited another time and you will be happy to chat to them more as and when they wish. *"I am very happy to talk to you about any concerns or questions you have about this now or later. Is there anything you would like to ask me about?"*

A nice way to introduce the concept of ACP is: *"Often people with conditions like yours have a lot of questions that are sometimes scary or sometimes they are not certain if they want to know the answers. People vary in how they want to make medical decisions and plan for future care. Some people want to do this themselves, some want to share this with the doctor. What would you like?"*



**"We want to understand what is important to you so that we can care for you in a way that you want us to. Have you thought about how you would want us to care for you if you become very sick, and are unable to tell us what you would want?"**

Some people also might want to have relatives and friends be a part of the discussion. Don't make assumptions. Ask *"Is there anyone you would like to include in this conversation?"*

Establish how much the person understands about their medical condition – *"What is your understanding of where you are with your health?"*

Find out what matters most to the person:

- *"What is important to you?"*
- *"What does a good day look like for you?"*
- *"What are your goals and priorities?"*
- *"What would you be willing to sacrifice or not sacrifice?"*

Find out if there is anything worrying the person:

- *"What are your biggest concerns at the moment?"*
- *"What are your worries about your future?"*

**Asking open-ended questions will encourage a conversation to flow.** Remember to use your communication skills, use an inviting tone and open body language. Encourage the person to ask questions and offer to support them with communicating the conversation with any person or people to whom they have given their consent for this purpose.



Always end discussions with a follow-up plan. People may need time to consider decisions, or reconsider what has been discussed. Advance care planning conversations should be ongoing.

Document the conversation and share the information with the healthcare team, including the GP and treating physician.

If a person has an advance care plan:

- Encourage them to tell their relatives and friends that they have an ACP, and that this document outlines **their** wishes for **their** future care.
- Suggest that the patient/resident discusses their ACP with any other healthcare teams they may be involved with (for example, other medical teams and treating consultants).
- Advise the patient/resident to keep a copy of their ACP where it can be easily accessed (for example, if they have a pre-packed hospital bag, to keep a copy in it).
- Advise them to take their ACP with them whenever they might transfer between care settings (for example, on admission to hospital, attending at the Emergency Department, transferring to nursing home).
- The **Think Ahead Planning Pack** is a customisable set of advance care planning tools developed by IHF. These documents allow a person to record their wishes and decisions in the event of serious illness, injury or death. It is available on [www.thinkahead.ie](http://www.thinkahead.ie)



## Advance Healthcare Directives

An Advance Healthcare Directive (AHD), sometimes known as a 'living will', is a statement about the type and extent of medical or surgical treatment a person would want or not want in the future if they lack capacity to make or express that decision at that later time.

Advance Healthcare Directives are important because they allow people to express their refusal or consent to any type of treatment, including life-sustaining treatments, ahead of time, in case they are later unable to do so for themselves. Any treatments a person refuses are legally-binding. A person may also name a Designated Healthcare Representative to consent and refuse treatments on their behalf. Having an Advance Healthcare Directive means there is no decision-making burden placed on family members or healthcare professionals because a person's healthcare decisions and preference have been made known. In the absence of an Advance Healthcare Directive, healthcare decisions will be made by the healthcare team. However, an AHD makes it easier for healthcare professionals too because they know what a person's wishes and preferences are in different healthcare situations that might arise.

In Ireland, Advance Healthcare Directives (AHD) are legally recognised. To make one, a person must be over 18 and have decision-making capacity. A person who has decision-making capacity can do all of the following:

- Understand information about the decision they are making, at the time the decision is to be made.
- Remember the information long enough to make a choice.
- Weigh up information as part of the process of making the decision.
- Communicate their decision by writing it down or by telling or showing someone what their decision is.

An AHD comes into effect when a decision needs to be made, but the person no longer has capacity to make or express that decision.

**As a staff member:**

- A person may ask you to help them make their AHD. It is ok for you to offer assistance, but they must be able to make the AHD by themselves, which means they must have decision-making capacity to do so.
- If a person has a specific illness or condition, you might want to advise them to talk to their treating physician about completing an AHD so that they can discuss what treatments are medically most appropriate for their condition.
- You can help them to think and talk about the treatments they do not want to have (refusing treatment) or do want to have (requesting or consenting to) in the future.
- Remember an AHD must represent the person's will and preferences and not anybody else's.
- You can help someone record their AHD by voice, video or assistive technology.
- If you have helped someone make an AHD, advise them to tell those who are important to them (their family and/or friends, GP and care team) and encourage them to share copies so everyone knows what is important to them.
- If a person has made an AHD, then you must consult it if the person loses their ability to make a treatment decision.
- If a person has made an AHD, then any requests for treatment in it should be taken into consideration and respected as far as possible, depending on the circumstances.

Your role as a healthcare worker is to respect a person's AHD. Remember they are the expert at what matters most to them.

For more information on Advance Healthcare Directives and the Think Ahead Planning Pack, visit [www.thinkahead.ie](http://www.thinkahead.ie)

The Assisted Decision-Making (Capacity) Act of 2015 fully legalises Advance Healthcare Directives, and came into effect in April 2023. More information can be found with the Decision Support Service ([decisionsupportservice.ie](http://decisionsupportservice.ie)) and the HSE ([assisteddecisionmaking.ie](http://assisteddecisionmaking.ie)).

Simple templates are available from the Decision Support Service. The Advance Healthcare Directive included in the Think Ahead Planning Pack is fully aligned with the current legislation. Visit [www.thinkahead.ie](http://www.thinkahead.ie)



# Care of the Dying Person

## Recognising when death is imminent

Diagnosing that someone is dying is a process with significant implications, and one which you as a healthcare worker can contribute to as a member of the multidisciplinary team. To plan for and provide the appropriate care needed by patients/residents and their families, it is important that the diagnosis of dying is made as early as possible. Timely recognition that a person is dying also enables the goals of care to be in line with the person's wishes and preferences outlined in their advance care plan for their end of life.

Patients/residents themselves may already be aware that they are dying, often before healthcare workers. They may have indicated a wish to talk about it. *"I'm not getting any better", "I'm coming to the end", "I'm not going to make it"*.

If you are caring for a person at the end of life, it is important that you respond to these cues by facilitating an open conversation. The person may have things on their mind that they need to discuss or sort out in their remaining time. *"What makes you ask that?", "Is there something that you are worried about?", "You are sick enough to die"*.

There are many possible signals indicating that a patient or resident is approaching death and entering the final stages of the dying process. It is important that these signs are recognised by healthcare staff, and you should consult appropriate colleagues and refer to local guidance around identifying these signs, and around how you should then proceed.

Care for people who are dying should be a continual process, with an emphasis placed on enabling an appropriate response to an assessment of their condition and symptoms they may have. It is important to take into account their wishes and preference, that are either expressed at the time, or as part of an advance care plan.

Clear, open and sensitive communication is important. If a person has entered the dying phase, then it is vital that this is communicated, in keeping with the person's wishes, to them and those they have designated, such as friends and relatives.

**Poor communication is often stated as a reason for complaints within health services.** Not communicating that a person is dying, or not understanding that death is close, can increase the distress felt by loved ones, and may have a negative impact on the subsequent grieving process.

There are resources available to support communications for those caring for people facing end of life in hospitals and nursing homes on [bereaved.ie](http://bereaved.ie).

It is important that the possibility that a person may die within the next few days or hours is communicated clearly to the person and the people they wish to know.

## The final hours - when dying is imminent

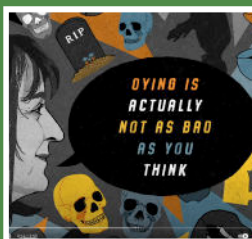
It can be difficult to predict when a person is nearing death. There are, however, signs that show death is approaching:

- The person becomes deeply unconscious, with no waking episodes.
- There is cooling of the hands and feet as blood is diverted away from the limbs to the torso.
- Their heartbeat is irregular.
- There may be stiffness in the limbs due to immobility.
- Their breathing pattern may have changed. There may be long gaps without breathing, followed by several big breaths. This intermittent pattern is called Cheyne Stokes breathing.
- Difficulties in swallowing lead to a build-up of saliva at the back of the throat. This can cause noisy breathing, often referred to as the death rattle. This can be very distressing to see. However, at this stage the person is so deeply unconscious that they are not caused any discomfort by this.

Other people may need your support to understand what they see as their loved one dies. More information about supporting grieving people is on [bereaved.ie](http://bereaved.ie).

### Useful Resource: Dr Kathryn Mannix

Dr Kathryn Mannix explains the dying process in a short BBC Ideas video 'Dying is not as bad as you think'.



Scan here to view.

## Spiritual care at the end of life

Spirituality is about finding meaning and purpose in life. Some people find their sense of spirituality in several ways:

- Our relationships (with friends, family, colleagues, carers).
- The arts, such as music, poetry, art, dance, drama.
- The environment, for example, nature, mountains, the sea, our garden.
- Our creativity, our work, our imagination, our hobbies.
- Religious practices, prayer, meditation, worship, etc.

The provision of spiritual care goes a lot further than addressing any religious needs that a person might have. The end-of-life care planning process should explore what spirituality means to a person, so that person-centred spiritual care is provided, to help them achieve a sense of peace in their heart. These are the kinds of questions you could ask:

*“What raises your spirits?”, “What gives you a sense of peace in your heart?”, “What brings you comfort?”, “In difficult times, where do you draw your hope and strength from?”, “Do you have any or spiritual religious beliefs?”*

To provide spiritual care to another person, it helps if we know and are aware of our own spirituality. When it comes to spirituality, ‘what is mine is mine, and what is yours is yours’, and even if we share common ideas or practices, the experience of spirituality is individual.

Providing spiritual care is about ‘being with’ rather than ‘doing to.’ Chaplains and other types of spiritual carers may be available to meet with patients, and are specifically trained to do so. However, even without this training, anybody who feels comfortable doing so can help a person feel accompanied (‘being with’) in their journey. It is about intimacy and sharing, using all of our senses, our spiritual intelligence, to be able to offer spiritual hospitality, drawing from our well of humanity to support another person to feel a sense of belonging and connectedness, a sense of peace.

Providing spiritual care at the end of life is like accompanying the person on their journey. As staff members, we have to acknowledge that this is their journey; our role is to journey with them in their way.

## Caring for a person who is dying

Remember, we only have one chance to get it right.

Caring for a person who is dying may make you feel uncomfortable. End-of-life care situations can remind us of our own mortality or bring up strong emotions connected to our own bereavements and loss. We may feel an overwhelming need to be ‘doing something to help’, yet we may be unsure of what that ‘something’ is.

End-of-life care is both unique and common. While every death is an individual experience for that person and their community, there are aspects of dying that are common to all deaths. Knowing this gives us the opportunity to expect and plan for the provision of the right care needed at this time.

**A person-centred approach to end-of-life care will involve:**

- Sensitive, open and honest communication and the provision of information
  - Use effective verbal and non-verbal communication.
  - Recognise the possibility that the person is dying, and make sure that this is clear to the person, their carers, friends, and family and the staff (in keeping with the person’s will and preference).
  - Prepare them for the person’s death.
- Physical care - assessment and management of distressing symptoms
  - Ensure the whole team are involved, including Specialist Palliative Care who may be required to support with complex symptom management.
- Psychological care for the person and their relatives and friends
  - Direct the person to the appropriate resources available.
  - Be alert to their emotional needs and offer them regular opportunities to discuss their concerns.
- Social care, spiritual care and complementary therapies
  - Provide spiritual care in keeping with the person’s will and preference. Remember spiritual care need not mean religious care.
  - Provide privacy for the person and those around them to have the social support they need.
  - Think about the environment, offer music, dim lighting, relaxation/massage therapies.
  - Informal care provided by family, friends, and neighbours.
- Bereavement support
  - Support the relatives and friends prior to, at the time of and after the death.
  - See additional resources on page 44.

**Ideally, when a person is dying, consider:**

<b>The person’s needs:</b>	<b>The relatives’ and friends’ needs:</b>	<b>Your role:</b>
<ul style="list-style-type: none"> <li>• To be comfortable</li> <li>• To feel that they are respected</li> <li>• To feel that they are at the centre of the care</li> <li>• To be included</li> <li>• To have their say</li> <li>• To be listened to</li> <li>• To be honoured</li> <li>• To be supported</li> <li>• To have privacy</li> <li>• To have clear information</li> <li>• To have their spiritual needs met</li> <li>• To be at peace</li> <li>• To have pain and symptoms managed</li> </ul>	<ul style="list-style-type: none"> <li>• To have their emotions acknowledged</li> <li>• To have their concerns addressed</li> <li>• To be listened to</li> <li>• To receive clear information</li> <li>• To be told the person is dying</li> <li>• To be included in care</li> <li>• To be linked with support services (social work, chaplain, etc.)</li> <li>• To be supported</li> <li>• To have privacy</li> <li>• Time to say goodbye</li> <li>• Time to process what is happening</li> </ul>	<ul style="list-style-type: none"> <li>• To keep the person at the centre of your care</li> <li>• To recognise that the person is dying</li> <li>• To be available to the person</li> <li>• To monitor and assess for signs of distress</li> <li>• To be available to others</li> <li>• To communicate clearly</li> <li>• To break bad news well</li> <li>• To listen</li> <li>• To allow for tears</li> <li>• To ensure the necessary team members are involved</li> <li>• To care for your colleagues</li> </ul>

## Considerations for infection control

The infection prevention and control procedures that are necessary in healthcare settings to reduce the transmission of infections and viruses (such as COVID-19 and others) can unfortunately negatively impact on the experience of end-of-life care. This is a difficult situation for everyone to be in. It is important to acknowledge these feelings and offer comfort and reassurance. Having clear communication channels to provide information and respond to queries is vital. This is particularly important if visiting restrictions are in place. Refer to your local PPPG (Policies, Procedures, Protocols, Guidelines) for more information.

HPSC and HSE guidance supports visiting to be facilitated for end-of-life care situations. For current guidance on infection prevention and control and visiting, see [www.hpsc.ie](http://www.hpsc.ie)

**IHF strongly recommends that priority be given to enabling visiting for patients and residents who are receiving end-of-life care.**

There needs to be clear communication of the reasons for any visiting restrictions and what alternative arrangements have been put in place so that important social connections are maintained. Visiting should be supported and enabled as much as possible by staff.

The use of a Visitor Pass can enable hospital security to know that visitors are attending a person who is receiving end-of-life care. This limits the need for visitors to explain why they are visiting the hospital to different members of staff.

## Supporting a person who is actively dying

- Is it possible to enable visitors to be present? **HPSC and HSE guidance supports visiting to be facilitated for end-of-life care situations.**
- If not, can it be arranged for a member of staff to be with the person at all times so they don't die alone?
- Your presence is so important at this time. Sit by the person's bed and offer a calming presence. Sometimes simply being there breathing with them can be soothing.
- Reduce noise and use dim lighting if possible.
- In the absence of friends and relatives and pastoral care, providing spiritual and psychosocial support is more important than ever. Remember that spirituality may not necessarily mean religion. Where a person does require support with their faith or religion, it is important to consider how you can provide this. You may be able to facilitate virtual pastoral care via a video call.



- Use the person's mobile phone to keep the connection with the people they love. Think about how you will access their phone (if they are unable) and pass messages on. Make sure a charger is available at all times.
- Encourage and help with the use of Skype, FaceTime or other video calling options to support a connection with others.
- Ask the person if you can help them make a voice recording or a video or take a photo.
- If the person is unconscious, talk to the person or read messages from their friends and relatives. If you can, set up the phone beside the person's ear and enable people to speak to their loved one.
- Ask them if there is anything they would like you to do on their behalf: read a prayer, play a song, say a poem, pass on a message, set up the phone near the patient's ear.
- Always assume the person can hear you.
- Reassure them that you are there with them, even if they are unconscious.

**At the time of death, pausing together for a moment in silence at the bedside is a simple but poignant way to honour the person. This would be particularly symbolic where loved ones were not permitted to be there or could not be there in the case of sudden death. It also helps staff to honour the person's death.**

## What to do if the person dies without their relatives and friends present

The details of the person's death are so important for others. Be prepared to tell the story.

*What was it like?*

*Who was present?*

*What were their last words?*

*Did you read to them/ pray with them?*

*Were they comfortable?*

*Did they open their eyes?*

*How did you care for them after they died?*

*How was the death acknowledged? (e.g., moment's silence, end-of-life symbol)*

*How long did they stay on the ward for?*

*What happened next?*



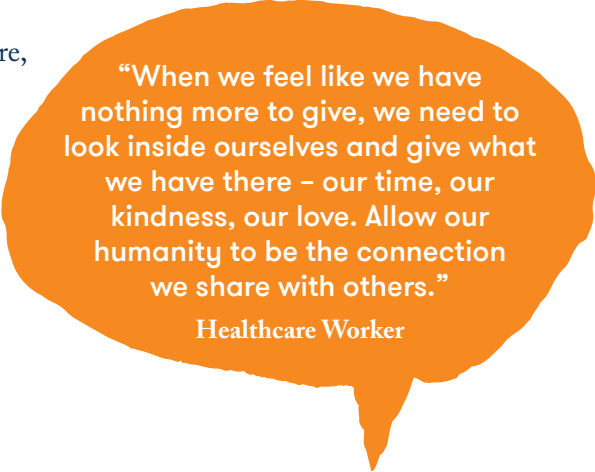
At a later date, you might like to send them a sympathy card.



## Supporting family and friends when a person is dying

Good end-of-life care also includes the support we give to the community surrounding a person - including family, friends and carers - before, at the time of and after death. While we always need to keep the person at the centre of our care, we should also aim to provide community-inclusive end-of-life care. We need to recognise those who usually provide the primary support for the dying person and acknowledge the importance of those relationships.

While all relationships are different, they each need care, kindness, compassion and time. When providing support for friends, family and carers, we need to be aware of diverse family situations and the individual dynamics of each particular family, as well as other important relationships to a dying person. We need to consider how emotional/psychosocial relationships, cultural and spiritual issues and how practical, environmental and financial concerns might impact the person dying and their family.



“When we feel like we have nothing more to give, we need to look inside ourselves and give what we have there - our time, our kindness, our love. Allow our humanity to be the connection we share with others.”

Healthcare Worker

### Supporting children

Parents and guardians who care for their children every day are usually the best people to communicate information to a child when a person is dying. Conversations to help children understand what is happening should take place as early as possible in the illness to allow the information to sink in. Then the child can ask questions later on, when they have had time to think. Talking to children about illness or death should be an on-going process (the timing will depend on whether it is a sudden or long-term illness). Children find it hard to take in too much information at once, so it should be broken down for them into small pieces with a little added to the story each time.

Visit [www.childrensbereavement.ie](http://www.childrensbereavement.ie) for more information.

### Communication

Good communication is important when supporting grieving people. All communication between staff and others should be governed by the known will and preference of the person and, where these are not known, by the best interests of the person. Friends and family can play an important role in helping to communicate with the person. Clear communication processes should be in place and adopted by all staff. These processes should involve the person and their Designated Healthcare Representatives, if any, to provide clarity around role and responsibility for decision making. It is useful to establish these processes as early as possible.

**Remember, nobody can make a decision for a person unless they have been legally appointed to do so by the person in an Advance Healthcare Directive.** Medical decisions should be made by the person for as long as possible, and then by any appointed person on their behalf. Barring the appointment of this person, medical decisions are made by a senior clinician.

Families, friends and carers may need support with both the practical and emotional aspects of a person dying.

**Here are some practical tips to support family, friends and carers when a person is dying:**

- Complete an information-sharing care plan. Have a discussion (and document) with the patient/resident about who is important to them and who they want to be included in their care, especially if:
  - Their condition deteriorates.
  - They are unable to make decisions for themselves.
  - Tests/scans/investigation results are available.
  - An emergency situation arises.
- Ask family, friends and carers if they would like to be involved in personal care, if this is something that the dying person would want. It is important to involve people at the level they wish to be involved – some may prefer to have a hands-on involvement, others may be happier staying further back.
- Suggest that people decide together how they are going to ask for and share information about the person, to avoid everyone calling the ward or care centre for updates.
- Encourage the dying person to communicate regularly with their relatives and friends – provide support with using a phone if needed, and ensure mobile devices are kept charged.
- Talk with friends, family and carers about the care and about any changes in the condition of the person. It can help to talk and explain about the dying process.
- Provide information timely and sensitively, giving consideration to privacy. Language should be clear and understandable, avoiding jargon. It is useful to provide written information, which can be taken away by relatives and friends.
- Encourage people to voice any worries or concerns they may have. *“What is your biggest concern at the moment?”*
- In keeping with the wishes of the person, flexible visiting arrangements should be in place. Some people may wish to be present with their dying person as much as possible, including staying overnight.
- Some people may come to you to talk or ask about different care or treatment options. If/when they do, remember that they are simply advocating for the patient.
- Prepare people, especially when death is imminent. *“Your mother is sick enough to die”, “Your mother is dying”*. If they are not aware of what is happening, they may miss the chance to say what they need to say to the dying person. Support them to be with their person, talk to them and touch them. Each person may need time on his/her own with the person who is dying but they may not feel they can ask for this. *“It might help if each of you spend some private time with your mother”*.
- Some people may be anxious about the conflicting demands on them – being with the person who is dying and caring for others. They may need acknowledgment that this is difficult, and reassurance that they can attend to others. *“It is ok for you to leave if you need to. We will call you immediately if there is any change.”*
- People often ask *“How long do you think they have?”*, *“Will it be tonight?”*. It is a difficult question. A good way to answer is *“We can never know for sure, but my advice to you would be, this is the time to say what you need to say, and if you do need to leave, then leave nothing unsaid if you go”*.



## Facilitating family meetings

When facilitating family meetings, it is useful to be aware of the fact that each family member is an individual with his/her own needs and coping skills/styles. It is also important to be alert to the possibility of family conflicts (old or newly-arising) and to ensure a safe place for people to express concerns.

Family meetings can provide the opportunity to:

- Create a shared approach to the care of the person who is dying. *“What would your mother want for herself if she could tell us?”*
- Listen to family members and clarify each person’s understanding of their relative’s condition. *“How do you think your mother is doing?”*
- Anticipate family members’ needs in terms of support. What are they struggling with most at the moment? *“I can see you are upset; how can I help?”*
- Enable their involvement in care, including symptom management, communication and assisting with the physical care needs of the person if they wish.
- Explore how the death of the person may impact, emotionally and physically, on different members of the family.

## Supporting families: additional considerations related to infectious diseases

Being prevented from spending precious time with a loved one as they come to the end of their life causes immense distress and anguish for everyone concerned. Those last few weeks, days, hours and minutes can be significantly important to some people. It’s the time to say those things that might have been unsaid before. It’s a time for forgiveness and reconciliation, a time for apologies and ‘I love you’. Visiting by friends, relatives and carers should be supported and enabled as much as possible by staff. **HPSC and HSE guidance supports visiting to be facilitated for end-of-life care situations.**

Being there for and with a loved one as they die can be a source of comfort for the bereaved. If this is prohibited, it can negatively impact on the grieving process.

**IHF strongly recommends that priority is given to those visiting people receiving end-of-life care.**

“I wasn’t allowed to be with Mum at the very end. I find it very hard to accept the fact that she has died. I think had I been able to bear witness to her death, I wouldn’t be feeling this way.”



## Here are some tips on supporting grieving people:

- It is important to acknowledge that this is a far from ideal situation. Offer comfort and reassurance that you will do everything possible to lessen the distress.
- Have clear communication channels available to provide information and respond to queries timely and appropriately.
- Accommodate alternate ways to maintain connections; like virtual and window visiting.
- Optimise the flow of information and communication; be proactive in this rather than reactive. For example, have a 'communication hour'. Let relatives and friends know the times the ward phone line will be operating and this is the time that they can call to get an update on their loved one.
- Provide clear information regarding the reasons for any visiting restrictions and also what alternative arrangements are in place.
- Clear one-page documents should be made available to explain to the general public what they can expect and plan for if they wish to visit their loved one – including, key guidance, who to contact, arrangements for use of iPads, etc.
- Provide people with the name of the person whom they can contact to get information about their loved one, in accordance with the dying person's wish and preference.
- Suggest that the Designated Healthcare Representatives act as a spokesperson between the hospital and other friends and relatives. If none was named, seek guidance on the dying person's known wish and preference to nominate a spokesperson.
- Have an open email address for people to email their messages in. These can then be collated through a central administration person who can then bring the messages to the ward to be passed on to the patients.
- Print copies or direct people towards Irish Hospice Foundation resources that provide information on what to expect when a loved one is dying and practical advice on what they can do. See Resources on Page 40 for more.
- Let families know there is information, including details of supports, available on [bereaved.ie](http://bereaved.ie)



# 5.

# Care after Death

## Care of the body after death

Care of the body after death is an ancient ritual providing an opportunity for people to offer a final mark of respect to the deceased person. These practices can have symbolic and cultural meaning. It is essential to plan and perform this care in keeping with the wishes of the person that has died. Refer to your organisation's 'Care After Death Policy'. Please refer to this for help and information with the practical aspects.

### Things to consider:

- In keeping with the principles of person-centred care, you should always allow for personalisation of after-death care in accordance with the deceased person's wishes and beliefs.
- Friends and family, as well as carers, might wish to participate in caring for the body after death. If so, as much as possible they should be facilitated to do so.
- Ensure people are fully informed of what is happening and what happens next.
- Reassure relatives and friends that you will take care of the person in death, just as you cared for them in life.
- Make sure that they know there is no hurry for them to leave, but equally, if they want to leave then that is ok too.

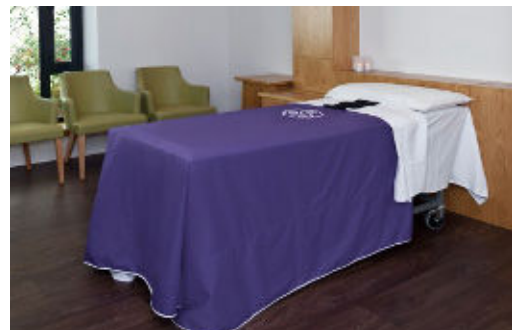
Staff members also may need support around the time of a death. Staff caring for a body after death can experience a range of emotions, especially if they have cared for the person for a prolonged time, or if the circumstances of the death were upsetting. Some ways to support staff members include:

- Ensure that the deceased person is treated with the same level of respect and dignity as when they were alive. It may also provide the opportunity for a staff member to say their own goodbye.
- Allow staff to talk about any feelings that may come up. Offer support and direct them to the appropriate resources available.
- Continue to talk to the deceased person as you move through their after death care.
- Take moments to pause while moving through after death care, such as the moment a person is covered with a sheet.

- Support colleagues after they have completed the after death care. Allow them a break to have a cup of tea or to get some fresh air. Allow them to reset themselves before they start their next task.
- Encourage your team to reflect and share together to express how you feel about providing care after death.

## End-of-life care ceremonial resources

A number of resources to support end-of-life care are available, for free and to purchase. Visit [www.hospicefoundation.ie](http://www.hospicefoundation.ie) for more information.



A universally recognised symbol that indicates the end of life. It's inspired by ancient Irish history and is not associated with any one religion or denomination. The three-stranded white spiral represents the interconnected cycle of life: birth, life and death.

The white outer circle represents continuity, infinity and completion. Purple is the background colour as it's associated with nobility, solemnity and spirituality.

## Providing care for those who are grieving for a person who has died

Caring for people at the end of life can be challenging, particularly after a death has occurred.

### Key messages:

- **Acknowledge** the loss: *"I am very sorry that your mother has died"*. Remember, even though the death may have been expected, it can still come as a shock. *"Death is always a shock, even when it is expected"*.
- **Validate** the person's feelings – people can experience a range of emotions when someone dies, from shock, through sadness, to anger and disbelief. It is important to validate that the person's feelings are normal and understandable given that their loved one has died. If someone who is bereaved expresses that they feel empty or angry or bewildered or nothing, you can respond by saying something like: *"That's very understandable given what has happened to you."* or *"Those feelings are not unusual given what has happened. Can I do anything to help you?"*

- Offer **support**: *“I am here for you”, “Is there anything I can do to help you?”, “Would you like me to call someone (priest/faith leader/family member/friend)?”*
- Stay with the relatives and friends until they settle. When you leave, **assure** them that you are nearby if they need you. *“I’m going to give you some privacy now. I am just outside if you need me”.*
- Give **support** as needed but make sure that people have some private time too. Invite people to take five minutes each alone with the person if they want. *“Would you like some time alone to say goodbye?”*
- **Address** concerns: *“Is there something I can do for you that will help?”*
- Provide **information**: *“You can stay as long as you want to, and you can leave when you are ready to. There is no need to rush anything”.*

## What happens next?

Often people will need support and information relating to practical matters after the death. It is important that you know the pathway of care following a death, so that you can answer questions and provide the information that people are looking for. It is good to have some written information available which details ‘what happens next’ in your care setting.

- Ensure dignity, respect and privacy for the deceased person at all times. Always refer to them by their name.
- Establish the deceased person’s preferences — check any documented notes of their advance care wishes.
- Offer **practical help**: provide refreshments; offer the use of a phone.
- **Explain** ‘what happens next’, particularly around the procedures for verification of death and care of the body.
- Offer them a private room where they can have a cup of tea and make phone calls if they need to.
- Administer care of the body, as per policy — invite the friends and relatives to play a part (e.g., fixing the person’s hair). *“Would you like to help fix your mother’s hair?”*
- When bringing the friends and family back in to view the deceased person, tell them how the person will look now. Approach the body first yourself. Touch the person’s head or hands and again acknowledge the loss. This simple gesture makes it safe for everyone. Stay a little while until people settle and then you can leave.
- Provide information about the pathway of care in your setting from here. For example, will the person be going to the mortuary? *“We will continue to care for your mother here until she goes to the funeral home”.*
- Ask if a Funeral Director has been appointed. If not, provide a list of local Funeral Directors.
- Ask if anybody would like to speak to a chaplain or a spiritual/faith leader.
- When they are almost ready to leave, return the person’s belongings in the Family Handover Bag.

The Family Handover Bag was developed to enhance care after death, in particular, the return of the deceased person’s possessions to their family. Items such as clothes and personal belongings can have huge sentimental value. It’s important that staff appreciate this and handle and record these possessions with care and return them to the family in a dignified and respectful manner.



Provide contact numbers and information on:

- Mortuary opening hours (if applicable).
- Post-mortem examination procedure (if applicable)
- How to collect the Death Notification Form.
- Bereavement support services.
- Remembrance services, etc.
- Chaplaincy services.



### Useful Resource: Intercultural Guide

Responding to the needs of diverse religious communities and cultures in healthcare settings



## Post-mortem examinations

For information about the processes and practices associated with post-mortem examinations in your local area, please contact your local Coroner's office. Contact details are on [www.coroner.ie](http://www.coroner.ie).

A post-mortem examination, also called an autopsy, is a medical examination of a person that takes place after death. The purpose of the post-mortem is to determine the exact cause of death.

There are two types of post-mortem (PM) examinations:

- A Coroner's PM
- A consented hospital PM

### A Coroner's PM

The core function of the Coroner is to investigate sudden and unexplained deaths so that a death certificate can be issued. The general rule is that all sudden, unnatural, violent or unexplained deaths must be reported to the Coroner. For the full rules regarding reporting deaths to the Coroner, please see [www.coroner.ie](http://www.coroner.ie).

Reporting a death to the Coroner does not necessarily mean that a PM examination will be performed. It is important to refer to your local Coroner for information about the processes and practices in your local area.

- A Coroner's PM is performed at the request of the Coroner by a pathologist who acts on behalf of the Coroner.
- Consent by the family is NOT required as this is a compulsory examination under the law.
- Formal identification of the deceased person must be carried out by a member of the family in the presence of a member of An Garda Síochána.
- All medical equipment must be left on the deceased person's body unless permission to remove it has been granted by the Coroner.



## A consented hospital PM

- Performed for medical education or research purposes.
- The cause of death must be known and the need for a Coroner's PM must have been ruled out.
- Performed at the request of the medical team.
- May be performed at the request of the family.
- Consent **is** required for the examination and also for the retention of tissues/organs.
- Family members can stipulate the limitations of a consented hospital PM (for example, what area of the body can/can't be examined).

## Communicating with family members about PM examinations

This can be a very distressing and difficult issue for families and needs to be discussed sensitively and explained thoroughly. Written information resources should be available to supplement the discussions held with family members. Family members should be given the contact details of a named person who can support the family through the whole process, and records of discussions and information given should be documented in the deceased person's healthcare record.

### Family members should be informed of the following:

#### A Coroner's PM:

- The reason for referring the death to the Coroner.
- The reason the Coroner has ordered a PM to be performed.
- The involvement of An Garda Síochána in the identification process.
- How and where identification of the deceased will be carried out.
- Family members need to know that their consent is not required for a Coroner's PM.
- Tissues or organs may be retained after the PM for diagnostic purposes.
- How the death is registered by the Coroner.
- When the results will be available.
- How the report will be available.

#### A consented hospital PM:

- The reason for the request for the PM.
- That consent of a nominated person (a family member or other contact person for the deceased) is required for the PM to be performed.
- That the family can stipulate the extent of the examination.
- That consent is required for the retention of any tissues/organs.
- How the death is registered.
- When the results will be available.
- How the report will be available.

### In both a Coroner's and a consented hospital PM, family members should be informed of the following:

- Where the PM will take place.
- How long the examination will take.
- If the PM will delay the funeral.
- What the examination may involve (for example, tissue samples, x-rays, clinical photographs).
- How the deceased person will look after the examination and how arrangements can be made to view the deceased person.
- Options regarding the return of tissues/organs to the family after the PM, including the option of the hospital disposing respectfully of the tissues/organs by cremation or burial.
- Further support and information resources, including bereavement support.

# 6. Caring for Staff

## Self-care in end-of-life care

Caring for people at end of life can be rewarding. People working in palliative and end-of-life care often describe feelings of great job satisfaction, gratitude and enhanced appreciation of the spiritual dimensions of life.

Healthcare workers tend to be people who are motivated to care for others. This predisposition, and the nature of care work itself, mean that particular attention is needed if staff are to avoid compassion fatigue and burnout.

Compassion fatigue has been likened to over-caring, or caring too much. It is often characterised by:

- An inability to switch off.
- Intrusive thoughts or dreams about work.
- Avoidance and withdrawal.
- Irritability.

If we do not attend to compassion fatigue especially if it is accompanied by overwork, it can lead to burnout.

Burnout is a defensive mechanism, which is characterised by:

- Emotional exhaustion.
- Detachment (not caring at all).
- Feelings of powerlessness.
- Cynicism.

None of these feel good and none of these are good for you as a staff member or as a person, or for the people that you are looking after.

If you are working with people who are facing dying, death and bereavement, it is useful to remind yourself of the following:

- You are not immune to grief.
- You need to take care of yourself in order to be effective and resilient in this work.
- You need to be supported in this work by the organisation (hospital or nursing home) in which you are working.
- You need to be aware of your own approach to loss and to death.
- You need to have a sense of what draws you to this work and what you get out of it.
- You need a safe place to process your own feelings.
- You need to have a sense of what helps you to stay healthy and committed to this work.

## Team care

Providing end-of-life care can be rewarding, yet challenging, work. It can be physically, mentally and emotionally demanding on staff members. **It is important to work together as a team and support each other.** Remember that a chain is only as strong as its weakest link.

### Here are some tips that you may find useful:

#### Collaboration and work environment

- If you don't already have team meetings, start them! As a team, acknowledge that end-of-life care can be rewarding and challenging. This is difficult work; not everyone can do it.
- Provide space, facilities and time for staff to be able to get away from the clinical environment to take their breaks. Ensure breaks are scheduled and taken.
- Develop local work practices that allow for increased support for staff when delivering end-of-life care, for example, buddying systems, re-distribution of tasks.
- Find ways to bring joy into the workplace; laughter is good medicine at appropriate times.

#### Reflection, kindness and gratitude

- Set aside regular opportunities for reflection. Reviewing and reflecting on the end-of-life care we provide gives us the opportunity to recognise when things go well, and to identify areas for improvement.
- It is important to be kind to yourself and others. Working as a team and appreciating that we need to support each other to be able to do this will help.
- At the time of a person's death, pausing together for a moment in silence at the bedside is a simple but poignant way to honour the person. This would be particularly symbolic where family members were not permitted to be there. It also helps staff to honour the patient's death and acknowledge the profound event that has happened.
- Appreciate and show gratitude when you see acts of kindness – *'Thank you for being there'. 'The way you spoke to that person was so tender and gentle'*. Getting positive feedback is rewarding and helps us all to confirm for ourselves that we are doing our best, that our actions and words count.
- Invest in taking the time for self-care activities, and offer support to your colleagues where you can. Remember that in all of this, we are never alone, always together.



## Suggestions for self-care

### Take breaks

- Take your rest breaks. We need to nourish ourselves to flourish.
- Call a 'time out' (usually, a few minutes is enough) as a way of dealing with emotional flooding after a traumatic event — for example, tell your colleagues that you need to take a five-minute walk or break.



### Practice mindfulness exercises

- As you walk from your car to your workplace or through the corridors of your workplace, attend carefully to the sensation of contact between your feet and the ground.
- Set your watch or telephone alarm for midday each day. Use this as a prompt to centre or ground yourself in the here-and-now (e.g., take 4 deep slow breaths, think of a loved one, recite a favourite line of poetry, prayer or a verse of song).
- Stop at a window in your workplace and notice something in nature — consciously give it your attention for a few moments.
- Regularly pause and bring your attention to the sensation of your breathing for 2 to 5 breaths.
- Use routine activities to stimulate your pauses – for example, every time you wash your hands, take a few deep breaths.
- Keep a notebook and write 'field notes' on traumatic or meaningful encounters and events.
- Deliberately develop a role-shedding ritual for the end of the day — for example, changing out of work clothes, using the drive home from work to sing, taking five minutes on the way home to breathe some fresh air, listening to music or audiobooks.

### Maintain social connections

- Deliberately make connections during the day with your colleagues, residents/patients and families and, where possible, use humour.
- Stay connected to the outside world during the day (e.g., phone home or check in with loved ones).

### Be kind to yourself

- It is important to be kind, caring and compassionate to yourself.
- Give yourself permission to do what you need to do to look after yourself, to care for yourself.
- Seek help from your colleagues, even if you're the one in charge!
- Supporting people to die well is an enormous challenge. Remember, it is often the small things that count the most. That's where you can make a big difference.



# 7.

## Useful Resources and Websites

On IHF's website, you will find resources, including videos, brochures and booklets, on a range of topics relevant to this toolkit.

Visit [www.hospicefoundation.ie](http://www.hospicefoundation.ie)

- Adult Palliative Care Services Model of Care for Ireland [www.hse.ie/eng/about/who/cspd/ncps/palliative-care/moc](http://www.hse.ie/eng/about/who/cspd/ncps/palliative-care/moc)
- All Ireland Institute of Hospice and Palliative Care [www.aiihpc.org](http://www.aiihpc.org)
- Bereavement Support Line 1800 80 7077 Mon-Fri 10am to 1pm
- Caru: Supporting Care and Compassion at End of Life in Nursing Homes [www.caru.ie](http://www.caru.ie)
- Decision Support Service [www.decisionsupportservice.ie](http://www.decisionsupportservice.ie)
- Health Protection Surveillance Centre [www.hpsc.ie](http://www.hpsc.ie)
- IHF Bereavement Hub [www.bereaved.ie](http://www.bereaved.ie)
- Irish Childhood Bereavement Network [www.childhoodbereavement.ie](http://www.childhoodbereavement.ie)
- National Clinical Programme for Palliative Care [www.hse.ie/eng/about/who/cspd/ncps/palliative-care](http://www.hse.ie/eng/about/who/cspd/ncps/palliative-care)
- Palliative Care booklet <https://hospicefoundation.ie/wp-content/uploads/2023/12/Palliative-Care-Booklet-Irish-Hospice-Foundation.pdf>
- Pregnancy and Infant Loss Ireland [www.pregnancyandinfantloss.ie](http://www.pregnancyandinfantloss.ie)
- The Palliative Hub <https://professionalpalliativehub.com>
- Grief in the Workplace [www.griefatwork.ie](http://www.griefatwork.ie)



### Information and Support around Grief & Bereavement

- **For staff and family and friends:** Information on grief and leaflets on bereavement are available from Irish Hospice Foundation (IHF) to read and download at [www.bereaved.ie](http://www.bereaved.ie) or by calling (01) 679 3188. These may be of use to both staff and family and friends who are bereaved.
- **To support children, teenagers and young people who are bereaved:** Information and leaflets on supporting children and young people who are bereaved can be accessed from the Irish Childhood Bereavement Network (ICBN) at [www.childhoodbereavement.ie](http://www.childhoodbereavement.ie) or by calling (01) 679 3188.

The Bereavement Support Line is a national freephone service run by Irish Hospice Foundation.

The BSL is for patients, family, friends, and end-of-life staff and carers.

- We aim to provide a confidential space for people to speak about their experience or to ask questions relating to the death of someone they cared about.
- We will listen to what a person says about what has happened.
- We will do our best to provide comfort and emotional support.
- We will provide any information that might help the caller, including information on practical supports.
- We will provide support for employers or professionals who want to inform the care their organisation can offer to bereaved colleagues.



Irish Hospice Foundation  
**Bereavement  
Support Line**  
**1800 80 70 77**



Monday to Friday 10am to 1pm



**Irish  
Hospice  
Foundation**

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

**[hospicefoundation.ie](https://hospicefoundation.ie)  
[info@hospicefoundation.ie](mailto:info@hospicefoundation.ie)**

*Irish Hospice Foundation. (2024).  
Toolkit for Compassionate End-of-Life Care (2nd ed.).*

Registered Charity Number 20013554