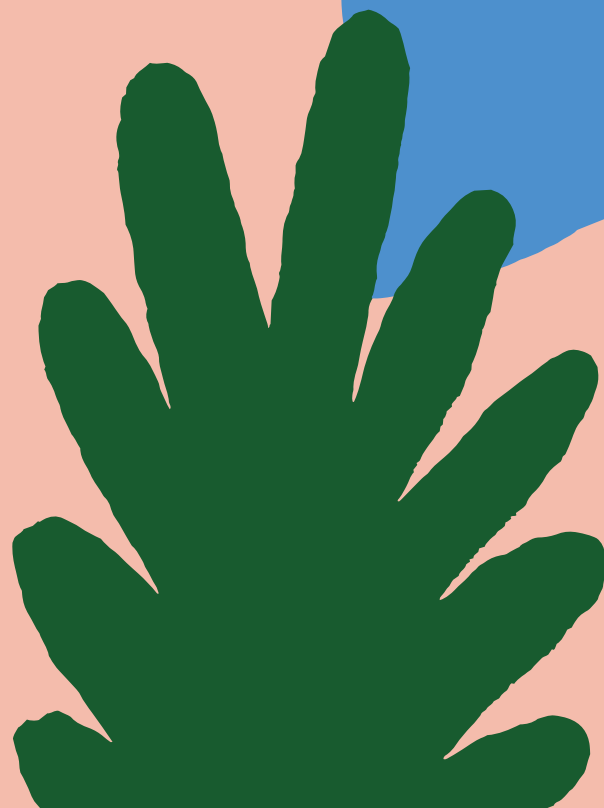
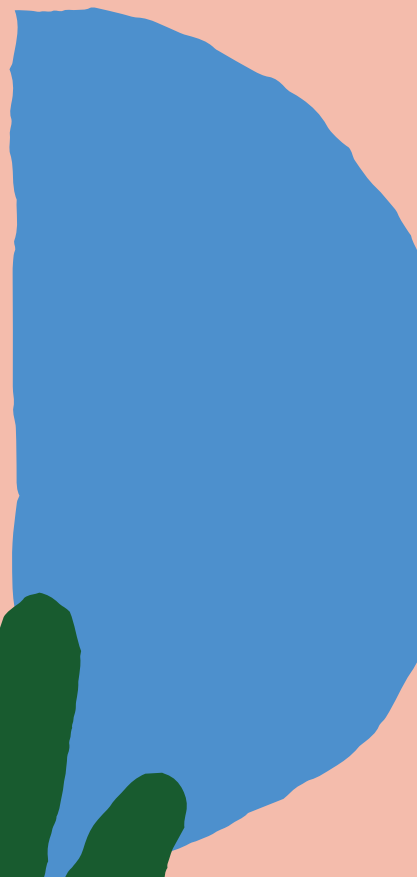


Toolkit

for Compassionate
End-of-Life Care



Irish
Hospice
Foundation

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Introduction

End-of-life care is everyone's business

Irish Hospice Foundation (IHF) is a national charity that addresses dying, death and bereavement in Ireland. We run a number of programmes to support staff in a range of settings including hospitals, nursing homes, primary care, etc. on issues related to end-of-life care and planning.

Our aim is that this Toolkit can be used by staff to support them in their everyday interactions with patients, residents and family members to provide a compassionate, person-centred approach to end-of-life care. It does not contain specific information about the medical management of symptoms associated with end of life. We would strongly recommend that advice be sought from your colleagues working in specialist palliative care, who can offer expert advice and support with this.

We believe that 'end-of-life care is everyone's business' and we would hope that all members of staff, regardless of their role will be able to find value in this Toolkit. It has been designed so it can be read in its entirety from start to finish, or the reader can dip in and out of sections that are most relevant to them at a point in time. The Toolkit aims to support the implementation of the *HSE Practitioner Guidance for Care of the Deceased Person* and other relevant HSE and HPSC guidance published in relation to care at the end of life and visiting.

This Toolkit has been written and compiled by IHF. The views expressed herein are those of IHF. Neither IHF nor any person acting on its behalf can be held responsible for any use made of the information contained in this publication. It is not intended to replace medical or legal advice.

January 2021



This Toolkit was developed in consultation with healthcare staff in acute hospitals, residential care and nursing home sectors, and our colleagues in bereavement support and education.

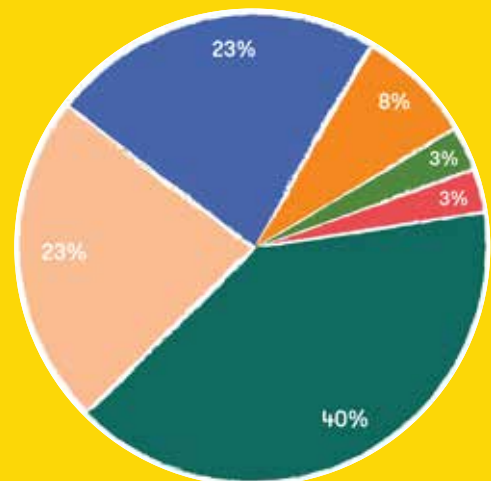
01. Dying in Ireland

Every day in Ireland, approximately 80 people die and 800 of us can 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 (right) using CSO figures from 2017.

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. Nationwide, there are currently 48 hospitals engaged with the HFH programme, which is now embedded within the HSE.



Place of Death - Ireland 2017:

- General Hospitals - including Acute, Orthopaedic, Psychiatric, Maternity, Paediatric, Oncology
- Home
- Nursing Homes & Community Hospitals
- Hospices
- Private Hospitals
- Elsewhere

CEOL (Compassionate End of Life) is a quality improvement programme for residential care facilities and nursing homes developed by IHF. It enables staff to deliver compassionate, person-centred end-of-life care to residents and their family members through a programme of training and development workshops, regional network events and ongoing supports.

More information on IHF healthcare programmes can be found on 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 which is 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 1-2 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 World Health Organisation (WHO) 2020 defines palliative care as ‘an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.’

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:



1

Level one: A 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 progressive and advanced disease will have their care needs met comprehensively and satisfactorily without referral to specialist palliative care units or personnel.

2

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.

3

Level three: Specialist palliative care:

- Specialist palliative care services are those services whose core activity is limited to the provision of palliative care. These services are involved in the care of patients with more complex and demanding 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 **palliative care approach** (Level 1)

02.

Communication

Getting the basics right

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

- Non-verbal (sometimes called our body language) communication – 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.

Here are some tips to help you make the most of your communication impact.

Non-verbal

- Always have your name badge where it can be clearly seen.
- Always try to have your eyes level with the person you are talking to. Avoid talking down to people (for example, if they are in a bed, you should sit to talk with them, don't stand towering over them). Sometimes, positioning your eyes at a lower level than the person you are talking to can be useful, this can make the person feel like they are more in control of the conversation and this might be useful in some situations (like advance care planning conversations).
- Be appropriately groomed – look clean, tidy and professional, you only get one chance to make a first impression.
- Make eye contact, a 1 – 3 second hold is normal, anything longer than that can start to feel uncomfortable. This can be culturally sensitive though; take your cue from the person you are talking to whether they are comfortable with more or less eye contact.

- 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 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 file of notes) as a barrier. Sitting at a 45-degree angle to a person allows them to have a comfortable level of personal space, which you can occupy without them feeling confronted.
- 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 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 facemask and Personal Protective Equipment (PPE). Remember these basics, use them to your advantage to make your communication more impactful.

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 facemask. Speaking a little slower should help you to be heard better by the other person.

Words

- Even though they account for a small amount of impact, the words we use are still very important. An inappropriate phrase can alter or undermine your message.
- Be clear, 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.

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

Maya Angelou

Discussing Dying: A useful resource

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.

<https://vimeo.com/170436673>

Communicating through Personal Protective Equipment (PPE)

With the impact of COVID-19 patients/residents and their families are finding themselves in a completely changed environment, where the need for strict infection prevention and control procedures is impacting 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 everyone 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 and family members, 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.

Your presence is your gift

If you're wearing PPE your body language, tone of voice and eye contact has never been more important. Your smile and warmth can be conveyed through your eyes, even if you're wearing a face mask.

Stress is contagious but so is calm

Be a calming presence. Move slowly if you can. Enter the person's room gently.

When you feel stressed or overwhelmed, taking three deep breaths is a quick way to steady yourself.

Try doing this every time you wash your hands.

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 family', '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'.*

Communicate Clearly and Honestly

- Use simple language as this helps people feel less confused.
- Always avoid jargon and euphemisms.
- Check if the person has a hearing aid or normally wears glasses – are these available, are the hearing aids working?
- Try not to avoid difficult questions. See sample phrases to open up a conversation.
- Give the person time, particularly if they are breathless or weak.
- Think of creative ways to demonstrate your message, use hand gestures, draw pictures, use photos, images or videos on a device.

SAMPLE PHRASES

Is that something you are worried about?

Would you like to talk about that?

Would it help if I...?

What can I do to help?

Breaking bad news

News is any information which seriously affects a person's view of their future¹, 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.



Five steps for breaking bad news:

1

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 not able to stay with the person while they process the news, make sure there is someone who can.

2

Step 2:

Make a good connection

- Welcome them, tell them your name 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 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.

1. Buckman R. (1992) How to Break Bad News, a guide for health care professionals. University of Toronto Press, Toronto

3

Step 3:

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

- Giving a warning shot allows them to prepare 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 shot to land.
- Gently deliver the news using clear simple language and avoid jargon and euphemisms: *“The lump in your breast is cancer”, “Your mother has died”.*
- 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 have talked about?”*

4

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?”*

5

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 the news. 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

1 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.



2 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.²
- **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.

3 Step 3: Warn them, and then be gentle as you deliver the news

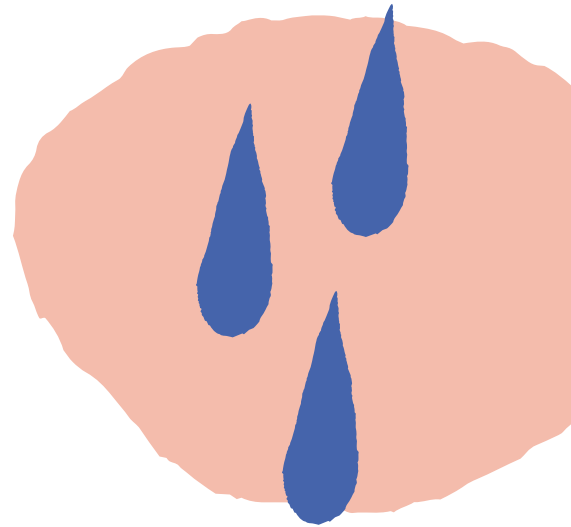
- Giving a warning shot allows them to prepare for what is coming next: *“I wish I had better news to give you today”, “I’m sorry, but the news isn’t as good as we’d hoped it might be”, “Unfortunately, I have some bad news for you”.*
- Pause. Allow the warning shot to land.
- Gently deliver the news using clear simple language and avoid jargon and euphemisms: *“The lump in your breast is cancer”, “Your mother has died”.*
- 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?”*

2. Buckman R. (1992) How to Break Bad News, a guide for health care professionals. University of Toronto Press, Toronto

4

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 understand this news must come 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?”*



5

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.
- 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:

1 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, intra-uterine death, stillbirth, neonatal death. Prepare yourself as much as you can to be able to support family members with both the practical and with 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 not able to stay with the person while they process the news.
- Do a top-to-toe check, this gives you a minute to ground yourself before you break the news, as well as checking your appearance. Pause and take some deep breaths.

2 Step 2: Make a good connection

- Introduce yourself, tell the family members 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 the family members' 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 the family members' current knowledge about what information gaps you may need to fill.

3 Step 3: Warn them, and then be gentle as you deliver the news

- Giving a warning shot allows them to prepare 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 warning shot to land
- Gently deliver the news using clear simple language and avoid jargon and euphemisms.
- Use the words dead and died. While this may seem blunt, it avoids the confusion that euphemisms like ‘passed’ and ‘passed away’ might cause.

4

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.

5

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 the family members that they are not alone and that staff are here 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.
- Give a warning shot 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 family members 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 the family on arrival at the hospital and ward or care centre.



Answering difficult questions

'These tablets are not doing me any good are they? 'I don't think I am going to make it, do you?'

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".

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, who 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 help. Your job is to accept that trust and explore their concerns with them. You don't have 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?"

The key is that conversations are allowed to happen, that the person is allowed to express themselves and ask for information, and that you as a staff member are willing to listen to them. Keep the conversation open, avoid closing it down.

"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.

"You are sick enough to die", "Your mother is sick enough to die"

"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:

- Try not to panic. Take a breath and pause before you answer.
- Don't avoid the question.
- Don't rush a response.
- Give the person your full attention and listen to them, really listen.
- Allow the person to express themselves, allow for silent pauses.
- Gently probe to find out what is on their mind.
- Remember, you don't have to have the answer, your job is to listen to them, and then provide the support they need to find the answer (which may be linking with another staff member). It's okay to say "I don't know" if you don't. It might be appropriate to say you cannot answer the question but you will try to find someone that can help.



- 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 persons feelings *"I can see you are very angry"*, *"I can see how upset you are"*.
- Second you should 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.

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 their family members 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.

- 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 family members. This can often 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?"*, *"Would you like me to call someone (priest/faith leader/family member/friend)?"*, *"There is no need to rush anything or any decisions 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"*, use the words dead and died.
- *"Things could be worse..."*

03.

End-of-Life Care Planning and Preparation

Advance Care Planning

Advance care planning (ACP) is the process of having meaningful conversations about what is important to a person and what they would want for their future care. 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 which consider a wide range of end-of-life matters, from place of care, to place of death, to making funeral arrangements.

The earlier the ACP process is commenced the better, particularly if any of the following are relevant:

- The person has a life-limiting, advanced progressive illness.
- If the person or their family have expectations inconsistent with clinical judgement.
- When there is a significant deterioration in the person's condition.
- When a treatment decision needs to be made.
- At the time of referring to Specialist Palliative Care services.
- When 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?”*

“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 not able to tell us what you would want?”

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?”*

Some people also might want to have family members or friends be a part of the discussion. Don't make assumptions, ask *“Is there anyone who 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 person³:

- *“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 to family members, once the person had given their consent for this.

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

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

If a person has an advance care plan:

- Encourage them to tell their family members 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/treating consultants).
- Advise the patients/resident to keep a copy of their ACP where it can be easily accessed, for example if they have a pre-packed hospital bag 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, transfer to nursing home).

³ Gawande, A. Being Mortal: Illness, Medicine and What Matters in the End. Profile Books Ltd. 2015



Think Ahead is an advance planning tool developed by IHF. The Think Ahead form allows a person to record their wishes about care in the event of serious illness or death. It is available on www.hospicefoundation.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, on the assumption that they will not be able to make that decision at the relevant time (citizensinformation.ie).

AHDs are important because they give people the opportunity to express their wishes now about **refusing** life-sustaining treatment at a time in the future when they may not be able to make that decision for themselves. Having an AHD means there is no decision-making burden placed on family members if a person's healthcare wishes and preferences are known to them. In the absence of an AHD, end-of-life 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 AHDs are legally recognised. To make an AHD 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 is only used if, at the time a decision needs to be made, the person does not have decision-making capacity.

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 treatment) 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 the 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.

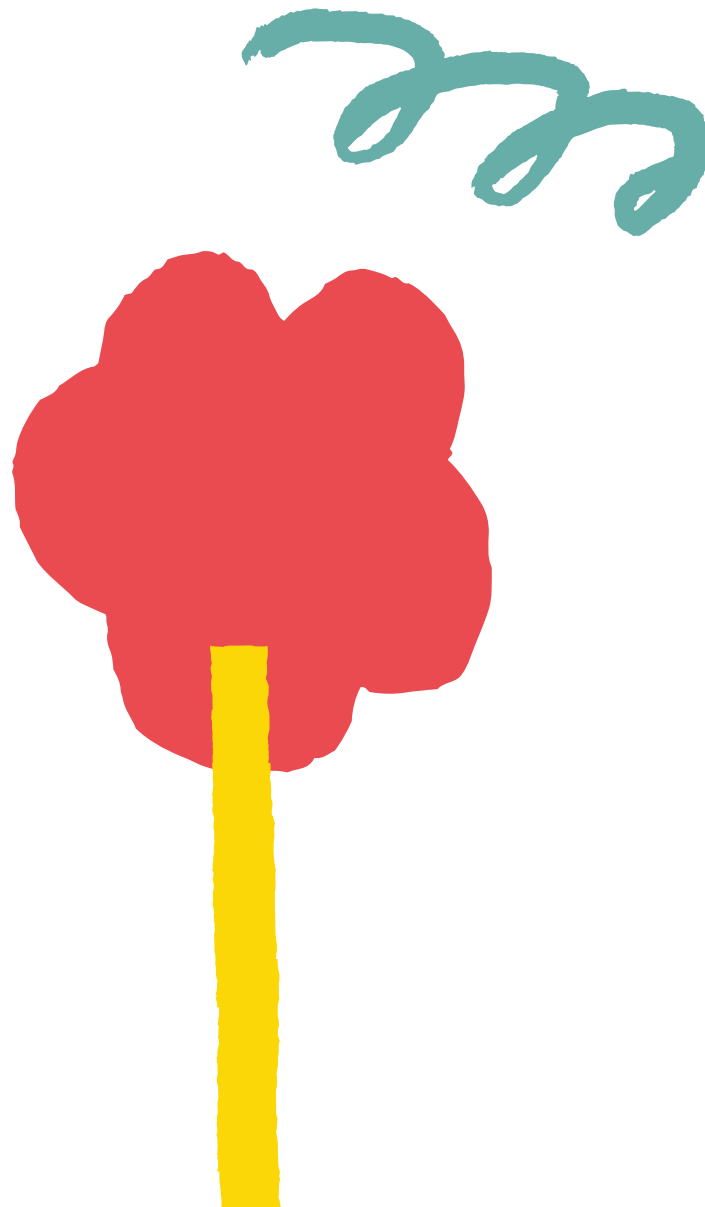
Your role as a healthcare worker is to respect a person's AHD. Remember they are the expert at what matters most to them.

For more information on AHD and the IHF Think Ahead form visit www.hospicefoundation.ie/

Note:

In Ireland, AHDs are recognised as valid under common law. Legislation has been passed to provide for statutory AHDs but it is not yet in effect. This is the Assisted Decision-Making (Capacity) Act 2015.

When the legislation comes into effect there will be an official template for the making of an AHD.



04.

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 signals indicating that a patient is entering the final stages of the dying process. It is likely that a person with advanced terminal illness with significant deterioration over recent weeks or months is entering into the dying phase when two of the four criteria listed below apply:

- They are confined to the bed.
- They have become semi-comatose.
- They are only able to take sips of fluids.
- They are no longer able to take oral medication.

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 their family members.

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 family members, and may have a negative impact on the subsequent grieving process. There are resources available that support this communication process on the **IHF Care & Inform online hub**:

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

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 their family (in accordance with the person's wishes).

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 trunk.
- 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.

Family members may need your support to understand what they see as their loved one dies. More information about supporting family members is on **IHF Care & Inform online hub**.

Useful resource

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



Spiritual care at the end of life

Spirituality is about finding meaning and purpose in life. We find our sense of spirituality in several ways:

- Our relationships (with God or with other people).
- 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.

“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 religious belief?”

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 a duty that all staff can attend to. It is about ‘being with’ rather than ‘doing to’. 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 that is dying

‘We only have one chance to get it right’

Caring for a person who is dying can 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 family, 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 family and the staff, (in keeping with the person’s will and preference).
 - Prepare the family for the person’s death.
- 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 family
 - Ensure the person has appropriate support.
 - Be alert to the emotional needs of family members 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 their family to have the social support they need.
 - Think about the environment, offer music, dim lighting, relaxation/massage therapies.
- Bereavement support
 - Support the family prior to, at the time of and after the death.

“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

When a person is dying:

The person needs:

- To feel that they are respected
- To feel that they are at the centre of the care
- To be included
- To have their say
- To be listened to
- To be honoured
- To be supported
- To be comfortable
- Privacy
- Clear information
- To have their affairs in order
- To have their spiritual needs met
- To be at peace

The family need:

- To have their emotions acknowledged
- To have their concerns addressed
- To be listened to
- Clear information
- To be told the person is dying
- To be included in care
- To be linked with support services (social work, chaplain etc.)
- To be supported
- Privacy
- Time to say goodbye
- Time to process what is happening

Your role:

- To keep the person at the centre of your care
- To recognise that the person is dying
- To be available to the person
- To monitor and assess for signs of distress
- To be available to the family
- To communicate clearly
- To break bad news well
- To listen
- To allow for tears
- To ensure the necessary team members are involved
- To care for your colleagues

Caring for a dying person, additional considerations related to COVID-19

The infection prevention and control procedures that are necessary in healthcare settings to reduce the transmission of the COVID-19 virus can unfortunately negatively impact on the experience of end-of-life care. Patients/residents, visitors, families and staff are finding themselves in a completely changed environment. 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 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.

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

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 by family members should be supported and enabled as much as possible by staff.

Example Visitor Pass



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

Supporting a person who is actively dying

- Is it possible to enable a family member(s) 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 family members 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 a virtual chaplaincy visit.
- Use the person's mobile phone to keep the connection with family members. 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 the family.
- 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 family. If you can, set up the phone beside the person's ear and enable family members to speak to their loved one.
- Ask the family 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 family members were not permitted to be there. It also helps staff to honour the person's death.



What to do if the person dies without their family present

The details of the person's death are so important for the family. 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 spiral)

How long did they stay on the ward for?

What happened next?

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

Supporting families when a person is dying

'Family' is defined as 'those closest to the person in knowledge, care and affection'. Remember that 'Family' is who the person says it is. Ask the person who is important to them, and who they would like to give information to about their condition. Sometimes a trusted friend might be more important to the person than a family member.

Good end-of-life care also includes the support we give to the family 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 family-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 families are different, they each need care, kindness and compassion and time. When providing support for families we need to be aware of diverse family situations and the individual dynamics of each

particular family. We need to consider how emotional/ psychosocial relationships, cultural and spiritual issues and how practical, environmental and financial concerns might impact.

Good communication is important when supporting families. All communication between staff and family should be governed by the wishes of the person and, where these are not known, by the best interests of the person. Family members 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 the family and provide clarity around role and responsibility for decision making. It is useful to establish these processes as early as possible.

NB: A family member cannot make a decision for a person unless they have been legally appointed to do so by the person (for example in an Advance Healthcare Directive). Medical decisions (especially decisions around resuscitation) should be made by the person, and if they do not have capacity, then the decision is made by a senior clinician.

Families may need support with both the practical and with the emotional aspects of a relative dying. It is important to be mindful of the issues that may arise within different death scenarios – for example: expected death, sudden death, violent death, the death of a child, miscarriage, intra-uterine death, stillbirth, neonatal death, etc.

Ways you can help, some practical tips:

- 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 members 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 family members at the level they wish to have – some may prefer to have a hands-on involvement, others may be happier staying further back.
- Suggest that larger families 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 person to communicate regularly with their family – provide support with using a phone if needed, ensure mobile devices are kept charged.
- Talk with the family members about the care and about any changes in the condition of the person. It can help to talk and explain about the dying process and explain. The resources *'When someone you care about is dying in hospital: What to expect'* or *'When someone you care about is dying in a nursing home: What to expect'* are useful to give to family. Visit [IHF Care & Inform online hub](#) for more helpful resources.

- 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 family members.
- Encourage family members 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. Family members may wish to be present with their relative as much as possible, including staying overnight.
- Family members 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 families, especially when death is imminent. *“Your mother is sick enough to die”, “Your mother is dying”*. If families are not aware of what is happening, they may miss the chance to say what they need to say to their dying relative. Support family members to be with their relative, 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”*.
- Family members may be anxious about the conflicting demands on them – being with the person that 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.”*
- Family members 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 COVID-19

Being prevented from spending precious time with a loved one as they come to the end of their life is causing immense distress and anguish for everyone concerned. Those last few weeks, days, hours and minutes are, for many people sacred times. 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’s. Visiting by family members 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:

“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.”

IHF strongly recommends that priority be given to enabling visiting for those people who are receiving end-of-life care.

How to support family members:

- 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 family connections, like virtual and window visiting.
 - Optimise the flow of information and communication with families, be proactive in this rather than reactive. For example, have a ‘communication hour’. Let family members know at home that at certain times – the ward phone lines 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 the family with the name of the person who they can contact to get information about their loved one.
 - Suggest the family nominate one spokesperson who can be the point of contact between the hospital and the family (with the consent of the patient).
 - Have an open email address for family members 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 families 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 in particular “When someone you care about is dying in a hospital/nursing home – What to expect”
 - Direct families towards **IHF Care & Inform online hub**.



05.

Care after Death

Last Offices

Last Offices - also known as the 'laying out of the dead' refers to the care of a patient's body after they have died. It is an ancient ritual providing an opportunity for people to offer a final mark of respect to the deceased person. The administration of Last Offices can have symbolic and cultural meaning. It is essential to plan and perform Last Offices in keeping with the wishes of the person that has died and their family. Precise procedural aspects of Last Offices should be in 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 persons wishes and beliefs.
- Family members might want to participate in the administration of Last Offices, they should be facilitated to do so if this is the case.
- Ensure family members are fully informed of what is happening and what happens next.

- Reassure family members that you will take care of the person in death, just as you cared for them in life.
- Make sure that family members 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. During Last Offices staff 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 common experiences are described below:

- If you have cared for someone it is natural that you may feel upset or anxious when they die. However, ensuring that the deceased person is treated with the same level of respect and dignity as when they were alive can be a source of satisfaction. It may also provide the opportunity for a staff member to say their own goodbye.

- You may feel scared about seeing a dead body for the first time. This is perfectly natural. Even if it is not your first time, you may feel this anxiety. Talk to your colleagues about how you feel. Ask for support.
- You might find parts of the procedure upsetting. It can be quite distressing removing the personal effects, such as the wedding rings, jewellery, or items that you know meant a lot to the person. You may feel like you are removing their identity or that you are treating them inappropriately. Talking to the person, and explaining what you are doing can make this a little easier.
- Covering the person with a sheet, or zipping up a body bag can be particularly distressing. It might help to take a moment to pause to recognise the finality of this act.
- Show support for your colleagues whom may have completed Last Offices, facilitate them to take a break to have a cup of tea or get some fresh air and allow them to reset themselves, before they launch into 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 are available to support end-of-life care. More information about these, regarding directions for use and where to purchase them from is available on www.hospicefoundation.ie



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. As staff members, we can be anxious about what to say and we may worry we might cause further upset to those who are grieving the death of a loved one.

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 family 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, especially partners/family members, 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 family members 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** to the family: provide refreshments, offer the use of a phone.
- **Explain** ‘what happens next’, particularly around the procedures for verification of death and Last Offices.
- Offer the family a private room where they can have a cup of tea, and make phone calls if they need to.





- Perform Last Offices, as per policy — invite the family to play a part (e.g., fixing the person’s hair). *“Would you like to help fix your mothers hair?”*
- When bringing the 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 family settles 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 the family would like to speak to a chaplain or a spiritual/faith leader.
- When the family are almost ready to leave, return the person’s belongings in the Family Handover Bag.
- Provide contact numbers and information on:
 - mortuary opening hours (if applicable).
 - Post mortem procedure (if applicable).
 - how to collect the Death Notification Form.
 - bereavement support services.
 - Remembrance services, etc.
 - Chaplaincy service.

Post Mortems

For the most up-to-date information on the Coroner Service please visit www.coroner.ie

For information about the rules and practices associated with post mortems exams in your local area please contact your local Coroner’s office, contact details are on 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 2 types of post mortem (PM) examinations:

- A Coroners PM
- A consented hospital PM

A Coroners 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.

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 rules and practices in your local area.

- A Coroners 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 the Garda Síochána.
 - **Please consult the local Coroner regarding reporting of deaths and identification process relating to COVID-19.**
- 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 Coroners 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.

A useful resource: *COVID-19 (Coronavirus): A guide for the bereaved* can be found at www.gov.ie

Family members should be informed of the following:

A Coroners PM:

- The reason for referring the death to the Coroner.
- The reason the Coroner has ordered a PM to be performed.
- The involvement of the 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 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 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.

06. Caring for Staff

Self-care in end-of-life care

Caring for people at end of life can be rewarding but it can also be very draining. Caring is emotional work. 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) that you are working for.
 - 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.
- It is important to be kind, caring and compassionate to yourself.
 - Take your rest breaks, and don't feel guilty about doing it. We need to nourish ourselves to flourish.
 - 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 or poetry, prayer or a verse of song.
 - 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.
 - Don't be afraid to seek help from your colleagues, even if you're the one in charge!
 - 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.
 - Stay connected to the outside world during the day, e.g., phone home or check in with loved ones.
 - Use routine activities to stimulate your pauses – for example, every time you wash your hands, take a few deep breaths.
 - Deliberately make connections during the day with your colleagues, residents/patients and families and, where possible, use humour.
 - Supporting people to die well at this time is an enormous challenge. Remember, it is often the small things that count the most. That's where you can make a big difference.

- 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.
- Give yourself permission to do what you need to do to look after yourself, to care for yourself.
- 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.
- 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,

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:

- 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.
- Set aside regular opportunity for reflection. Reviewing the end-of-life care we provide, and reflecting on it gives us the opportunity to recognise when things go well, and to identify areas for improvement.
- 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.
- Find ways to bring joy into the workplace, laughter is good medicine.
- 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.



07. Useful Resources and Websites

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

Visit www.hospicefoundation.ie

Health Protection Surveillance Centre www.hpsc.ie/

HSE Practitioner Guidance for Care of the Deceased Person www.hse.ie

COVID-19 (Coronavirus): A guide for the bereaved www.gov.ie

All Ireland Institute of Hospice and Palliative Care www.aiihpc.org

The Palliative Hub www.professionalpalliativehub.com/about/aiihpc

National Clinical Programme for Palliative Care www.hse.ie/eng/about/who/cspd/ncps/palliative-care/

Adult Palliative Care Services Model of Care for Ireland www.hse.ie/eng/about/who/cspd/ncps/palliative-care/moc/

Pregnancy and Infant Loss Ireland <https://pregnancyandinfantloss.ie/>



IHF Bereavement leaflets

Available to download from the website or order by contacting Irish Hospice Foundation

- The Grieving Family
- Grieving the Death of Someone Close
- Grieving the Death of Someone Close (Polish translation)
- Death of a Partner
- Death of a Same Sex Partner
- Death of a Parent
- Death of a Child
- Children's Grief
- Adolescent Grief
- Talking to Children About Traumatic Death
- Supporting Someone Who is Grieving
- Grief in the Workplace
- Bereaved by Suicide
- Grief at Christmas
- Death of a Pet

IHF COVID-19 Care & Inform online hub

As a national charity that addresses dying, death and bereavement, we have developed our COVID-19 'Care & Inform' information and advice hub to respond to the COVID-19 emergency in an informative and compassionate way. All of our information is in line with current HSE and Government guidance.

The COVID-19 Care & Inform Hub includes a range of information resources and videos focusing on the themes of grief, funerals in exceptional times, planning ahead and a suite of resources for healthcare workers to support and guide all who need it during this time. It is updated continually.

Click here
for our COVID-19
Care & Inform
resources



Bereavement Support Line

IHF Bereavement Support Line, in partnership with the HSE, has been launched to provide connection, comfort and support and to provide a confidential space for people to speak about their experience or to ask questions relating to the death of someone during the COVID-19 pandemic and/or a previous bereavement which feels more difficult at this time.

It is a national freephone service 1800 80 70 77 available from 10am to 1pm, Monday to Friday.





Irish Hospice Foundation

To die and grieve well wherever the place

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