National Healthcare Communication Programme

End-of-Life Conversations

ORGAN DONATION

A leaflet for healthcare staff

Making conversations easier

HSE

Introduction

Who this card is for

This skills card is for doctors and nurses who are holding end-of-life and organ donation conversations with families in Ireland. It is designed to support your existing communication skills and clinical judgement.

It does **not** replace clinical judgement, legal guidance, or national/local organisational policies on end-of-life care, consent, or organ donation.

The card assumes familiarity with national/local procedures for brainstem testing and referral to organ donation services.

Scope

- Focuses on **adult** potential organ donors in hospital settings.
- Assumes familiarity with local procedures for brainstem testing and referral to organ donation services.
- Can be used both for **training and reflection** and as a **quick-reference guide** in practice.

Introduction

Note on the examples

To support readability, the skills card sometimes uses a single example patient and family:

- **Patient:** Áine
- **Relatives:** her parents

These examples are fictional, but they are based on real experiences shared by families and healthcare professionals.

When you may need to pause or seek additional support

Consider pausing the conversation, seeking support from colleagues, or involving senior staff or the specialist organ donation team if:

- The person you are speaking with may lack capacity to make these decisions.
- There is a high level of unacknowledged distress, anger, or conflict that has not yet been acknowledged or stabilised.
- There is disagreement within the family or between the family and the clinical team about the goals of care or the diagnosis of death.
- There is a significant language or cultural barrier and an appropriate interpreter or cultural mediator is not present.

Introduction

> *High-quality care includes a partnership with families, built on open, two-way communication and respect.*
>
> **— Inspired by Azoulay et al.**

Azoulay E, et al. Family-centred intensive care: from information to communication and partnership (family-centred critical care literature, 2010s).

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Preparing for the conversation

Aim

To ensure you, the environment, and the information are prepared so that the conversation can be as supportive, clear, and safe as possible.

Communication skills

- [ ] Prepare your information
- [ ] Prepare the environment
- [ ] Prepare yourself

Prepare your information

- Gather as much relevant information as you can **before** meeting the family:
  - Clinical situation, prognosis, and what has already been explained.
  - Results and timing of any brainstem testing.
  - Any known wishes of the patient about end-of-life care or organ donation (e.g. donor card, conversations, advance directives).
  - Relevant legal or organisational requirements.

Preparing for the conversation

Prepare your information *(Contd.)*

  - Check the opt-out register and any known donor preferences, in line with national legislation and local procedures.
- Clarify with your team who will lead the conversation and who will support, including involvement of the organ donation nurse manager.

Prepare the environment

Whenever possible:

- Choose a quiet, private space without interruptions.
- Turn off or silence phones and pagers, or hand them to a colleague.
- Arrange for clinical cover for urgent tasks while you are with the family.
- Plan the seating arrangement carefully. Consider a gentle 90-degree angle or semi-circle rather than sitting directly opposite across a desk.

Preparing for the conversation

Prepare the environment *(Contd.)*

  - Place chairs at a distance that respects personal space but allows for closeness and support.
  - Consider a gentle **90-degree angle** or semi-circle rather than directly opposite across a desk.
  - Where possible, use chairs of the **same height**. If chairs differ, offer the higher chairs to family members.
- Remove physical barriers that can feel distancing (large folders, laptops between you and the family, coffee cups in hand).

Preparing for the conversation

Prepare yourself

- Ensure phones and other devices are **switched off or on silent**.
- Take a brief moment alone, if possible, to **settle yourself** and clarify your purpose:

> *I am here to support this family, to explain clearly, and to help them with an incredibly difficult decision.*

- Acknowledge internally that this will likely be emotionally demanding. Remind yourself that you cannot fix their distress; your role is to support, **inform, and accompany.**

Preparing for the conversation

TIP

“

In spite of all similarities, every living situation has, like a newborn child, a new face, that has never been before and will never come again.
(Martin Buber)

Each family and situation is unique. Aim to be fully present with this family, in this moment.

Initiating the conversation

Aim

Begin by creating as much safety and clarity as possible.

Communication skills

- [ ] Offer a warm greeting
- [ ] Introduce yourself and your role in simple language
- [ ] Check and use family members' names and how they prefer to be addressed
- [ ] Involve the person or people who are key decision-makers

Establish initial rapport

Offer a warm greeting

- Begin with a **warm, respectful greeting** and a warm facial expression. Use steady (but not fixed) eye contact.

Initiating the conversation

Introduce yourself and your role in simple language

- Introduce **your name and role** in plain language.
- If the family are not expecting a discussion about organ donation, avoid introducing someone solely as "*the organ donation nurse*". Instead, you might say, for example:

Initiating the conversation

Check and use family members' names and how they prefer to be addressed

- Check family members' names and how they prefer to be addressed:

> *You're Kathleen and Peter, is that right? How would you like me to call you?*

Involve the person or people who are key decision-makers

> *I can see this is very hard for you Peter.*

- Use their names from time to time, especially when expressing empathy or acknowledging something important:
- Avoid over-using names in a way that may feel artificial or insincere.

Initiating the conversation

Involve and orient the family

- Check early on what the family understand so far about Áine's condition and why they have been asked to meet.
- Check that they can **hear and understand** you; attend to basics like seating, temperature, and having tissues available.
- Briefly **explain the purpose and structure** of the conversation:

> *There are two important things we need to talk about today. First, what the tests show about Áine's condition, and second, what that means for decisions that may need to be made. I'll explain each step and there will be time for your questions.*

- Ask permission to proceed:

> *Is now an okay time to talk about this?*

> *Do you feel able to have this conversation now?*

Initiating the conversation

Express appreciation and condolences

- Thank them for being there and for their time:

> *Thank you for coming to talk with us at such a difficult time.*

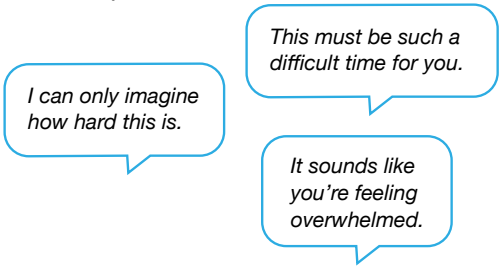
- Offer brief, sincere condolences, fitted to what they are likely to know at this point:

> *I'm so sorry about what has happened to Áine and to all of you.*

Initiating the conversation

Demonstrate empathy (without claiming full understanding)

- Acknowledge the difficulty of what they are facing, using language that signals care without claiming to fully know their inner experience:



- **Avoid** phrases such as:
  - *"I know exactly how you feel."*
  - *"I completely understand."*

  These can sound patronising or insincere because no one can fully know another person's inner experience.

Initiating the conversation

Supportive non-verbal behaviour

Communication skills

- [ ] Open body language
- [ ] Leaning
- [ ] Managing space
- [ ] Warm facial expression
- [ ] Eye contact
- [ ] Nodding & tilting
- [ ] Touch (when appropriate)
- [ ] Gestures
- [ ] Mirroring
- [ ] Vocal cues and invitations

You will already have all the non-verbal skills you need, what is important in these conversations is putting the right ones together at the right time. Take care to avoid suggesting non-verbally that you are uncomfortable or overwhelmed, for example by frequently checking the clock or looking towards the door.

Initiating the conversation

Where there is conflict, evidence of distrust, or complaints by family members, keep your non-verbal behaviour calm, grounded, and respectful.

Open body language

- Remove barriers (desk clutter, folders, phones, coffee cups in hand).
- Uncross your arms and legs. Face the family with an open posture.

Leaning and space

- Lean slightly **forward** to show interest, curiosity, and engagement.
- Use personal space that feels comfortable (often around arm's length), adjusting based on their non-verbal cues and cultural norms.

Initiating the conversation

Facial expression and eye contact

- Maintain a **warm, calm facial expression**.
- Use **appropriate eye contact** to show attention and care (avoid an unrelenting gaze that may feel intrusive).
- When you pause or allow silence, maintain gentle eye contact so they sense your ongoing attention and permission to speak.

Nodding and head tilt

- Gentle nodding can signal empathy and encourage the person to continue speaking.
- A slight **head tilt** can convey interest and willingness to listen:

Initiating the conversation

Touch

- Touch can sometimes be experienced as supportive (e.g. handshake, light touch on the arm or shoulder if the person is upset), but it can also feel intrusive.
- Move your hand slowly and watch their response. If they lean in or do not withdraw, touch may be welcome; if they move away, avoid touch.

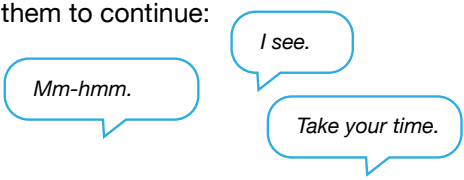
Gestures and mirroring

- Keep your hands visible; this can help others feel more at ease and build trust.
- Moderate gestures can add emphasis and meaning to what you say.
- You can **mirror** aspects of their body language, facial expressions, and speech patterns in a subtle way to foster connection – but avoid mirroring negative or agitated behaviours.

Initiating the conversation

Vocal cues and invitations

- Use a **warm, steady tone of voice**, at the lowest comfortable pitch for you. This often conveys confidence and calm.
- Nervous, high-pitched speech can be experienced as anxious or untrustworthy.
- Use short **vocal invitations** to encourage them to continue:



TIP

Non-verbal communication includes everything apart from the actual words: tone of voice, pace and volume, eye gaze, facial expressions, nodding and head movements, gestures, posture, and body movements such as leaning in or turning towards someone. Paying attention to these signals—both yours and theirs—can make a crucial difference.

Gathering information

Aim

To understand the family's perspective, knowledge, concerns, and emotions before giving detailed information or raising organ donation.

Communication skills

- [ ] Use open questions
- [ ] Clarify and screen
- [ ] Active listening
- [ ] Attend to non-verbal cues
- [ ] Use silence and effective pauses
- [ ] Reflective listening

Use open questions

- As a general principle, **gather before you give.** [1–3]
- Spend time understanding the family's perspective before providing more information or moving to decisions.

I've read the notes and spoken with the team, but I'd really like to understand how things are from your point of view.

Gathering information

Use open questions *(Contd.)*

- Use open questions, often starting with **what, how, when, where, who:**

What have you been told so far about Áine's condition?

How does this situation seem to you now?

- Follow up with more focused questions as needed:

Can you tell me more about that?

You mentioned X. Could you explain a bit more what you mean?

Clarify and screen

- Use clarifying questions to ensure you understand:

When you say X, what does that mean for you?

Tell me a bit more about that?

- Screen at natural pauses:

Is there anything else you're worried about?

Are there other questions or concerns on your mind?

Gathering information

Active listening

- Show you are listening:
  - Eye contact
  - Nodding
  - Leaning slightly forward
  - Neutral verbal encouragers (e.g. "*Mm-hmm*", "*Okay*", "*I see*", "*Right*")
- Avoid interrupting, even if you notice misunderstandings or disagreement. This allows them time to organise their thoughts and can reduce conflict.
- If there are complaints, mistrust, or disagreement, let them **finish what they want to say** before responding.
- Convey a caring, unhurried presence through your **tone of voice, facial expression, and posture**, even when under time pressure.

Gathering information

Attend to non-verbal cues

- Pick up on any non-verbal cues: expression, body language and tone of voice can give you clues about how people are feeling and what matters most to them.
- Allow time for the family to talk without interruption. Wait to begin your responses or information-giving until the family seem to be coming to the end of what they have been talking about.

Use silence and effective pauses

- **Listen without interrupting** (even if what they say suggests misunderstanding). This allows time for the person to collect their thoughts.

Gathering information

Reflective listening

- Reflect both **content** and **emotion**:

  Content:

  > *So from your point of view, things moved very quickly and you didn't feel fully informed.*

  Emotion:

  > *It sounds like that was very upsetting for you.*

- Notice if they repeat certain words or show strong emotion around particular parts of the story; these may mark what is most important to them.

Note: If this is a conversation in which family members are fully expecting to hear results of brainstem testing, move into giving the results early in the conversation.

TIP

Gathering information first allows you to fit what you say to the family's understandings and emotions. It can also bring misunderstandings to the surface early—before they fuel disagreement later on.[1–3]

Gathering information

Mistrust, disagreement, complaints

These core skills for gathering information apply throughout this sub-section on mistrust, disagreement, and complaints.

Communication skills

- [ ] Use questions to understand
- [ ] Active and reflective listening
- [ ] Non-verbal behaviour
- [ ] Demonstrate empathy

Use questions to understand

- You can reduce the chances of distress or conflict disrupting the conversation by **actively inviting** family members to share concerns, misunderstandings, or complaints early on.
- Understanding these early helps you to:
  - Build rapport and trust
  - Address misunderstandings before they escalate
  - Tread carefully where there is clear mistrust or disappointment.

Gathering information

Mistrust, disagreement, complaints

Active and reflective listening

- When family members are talking about events, what they are feeling, and why, **avoid stepping in too soon**. Let them speak until there is a natural pause.
- Avoid language that sounds like **taking sides** about what has or has not happened. Instead, focus on the impact on them and on their feelings.[6]
- Use reflective statements that focus on their experience and feelings rather than taking sides:

It sounds like you're feeling overwhelmed and unsure who to trust right now.

You're worried that things have moved too fast and that there might be something else that could be done.

Non-verbal behaviour

- Even if you feel discomfort or defensiveness internally, aim to keep your **non-verbal behaviour calm and neutral**.
- Maintain open posture, a level tone of voice, and facial expressions that show concern but not judgement.

Gathering information

Mistrust, disagreement, complaints

Demonstrate empathy

- Acknowledge and validate their distress without necessarily agreeing with the details of the complaint:

> *It sounds like it's been a very tough and stressful time for all of you.*

> *I can imagine that must have been really distressing.*

> *I can hear that you're really angry about that.*

- You are showing agreement that their **feelings** make sense, not that their account of events is necessarily factually correct. This kind of empathy helps keep conversations more harmonious and on track.[13]

Gathering information

Mistrust, disagreement, complaints

TIP

You cannot ‘fix’ the family’s distress, but you can provide support and use communication skills that help keep the conversation on track and make decisions possible. Sometimes, even with good communication, family members may not wish to collaborate. In that case, you may need to end the conversation by summarising your understanding of their perspective and outlining possible next steps.

Responding to emotion G.I.V.E.

Aim

To respond to emotion in a way that recognises and validates feelings, without rushing to fix or move past them.

Communication skills

- [ ] Get the emotion (non-verbal empathy)
- [ ] Identify the emotion (name it gently)
- [ ] Validate the emotion
- [ ] Explore to understand more

When you notice emotion – G.I.V.E.

Get the emotion
Identify the emotion
Validate the emotion
Explore to better understand

GET the emotion

Show **non-verbal empathy** by:

- Allowing silence.
- Offering tissues or water when appropriate.
- Staying seated and grounded, rather than rushing to end the conversation.

Responding to emotion G.I.V.E.

IDENTIFY the emotion

- Make an educated guess about what they may be feeling and name it gently as a possibility:

It looks as though this is very upsetting.

It sounds like you're feeling very shocked and overwhelmed.

VALIDATE the emotion

- Acknowledge that their feelings make sense in the circumstances:

Anyone in your position would find this incredibly difficult.

It's completely understandable that you'd feel this way.

EXPLORE

- If they seem willing, invite them to say more so you can understand better:

Would you like to tell me a bit more about what feels hardest right now?

Is there anything you haven't had a chance to say yet?

What's worrying you most at the moment?

Responding to emotion G.I.V.E.

TIP

Your role is to accompany and support, not to remove or “fix” grief.

Providing information and planning

Aim

To give clear, accurate information about the patient's condition, brainstem testing and death, and the possibility of organ/corneal donation, in a way that is structured, paced, and sensitive.

Communication skills

- Provide structure
- Use easy-to-understand language
- Chunk and check
- Slow down
- Watch for and respond to non-verbal cues
- Repeat and summarise
- Validate the complexity
- Allow time and opportunity for people to contribute

These core skills for providing information and planning apply throughout the following sub-sections for:
– Delivering bad news
– Brainstem testing and death
– Organ and corneal donation

Providing information and planning

Delivering bad news

When sharing very serious or life-changing information, consider a stepwise approach:[1–3]

Communication skills

- [ ] Provide structure
- [ ] Move gently step by step
- [ ] Warning shot
- [ ] Recap the story
- [ ] Use clear, non-technical language
- [ ] Repeat key information
- [ ] Give the family time
- [ ] Offer condolences

Provide structure

- Avoid bluntly raising or announcing highly sensitive topics (including organ donation) or bad news (for example, that brainstem tests show the patient has died). Sudden, blunt announcements can provoke shock and severe emotional reactions which may derail the conversation.

Providing information and planning

Delivering bad news

Provide structure *(Contd.)*

- When it becomes clear that family members do not fully recognise that their loved one has died, broach this gently, using skills that help people come to an understanding of bad news and reduce the chances of severe distress, shock, and upset.[1,11]

Move gently step by step

- Move gently and step-by-step into giving the bad news and helping family members come to a recognition of that news.[1–2]
- Give hints and clues to help family members recognise that unwelcome news is on its way. A step-by-step approach allows them to move gradually towards recognition of the news.

Providing information and planning

Delivering bad news

Warning shot

- Use a **warning shot** or **wish statement** to signal that the news is not what they were hoping for. For bad news, for example:

> *I'm sorry, it isn't the news you were hoping for.*

> *I wish we had better news to give you.*

  Wish statements convey a compassionate stance while also warning that unwelcome news is coming.
- When moving towards highly sensitive topics and decisions such as organ donation, use similar warning shots, for example:

> *I would like to raise something with you that is a very sensitive matter. It is something you will need to make a decision about on [patient name]'s behalf.*

> *I know you've had to deal with a lot over the last couple of days, but there is something important we need to talk through with you, something people sometimes find difficult to talk about.*

Providing information and planning

Delivering bad news

Recap the story

- Recap the 'story' of what has happened so far, in a way that points towards the news, using clear and simple language. For example:

> *As you know, [patient name] has had a very severe brain bleed, and they haven't been able to breathe without the ventilator since then. And you'll recall that two doctors were separately going to do brainstem tests this morning…*

- Use a steady pace and a compassionate tone of voice. Pause between phrases and sentences to allow the family to follow.
- Sometimes families may effectively deliver the news and ask you to confirm it. In those situations, you can gently confirm and support them in what they have understood. "*Are you saying that [patient name] is dead?*"). When this happens, confirm clearly and gently.

Providing information and planning

Delivering bad news

Use clear, non-technical language

- Ensure that you state the news in clear, non-technical language, and avoid ambiguous phrasing such as "*critically ill*" or "*very poor prognosis*" when you are communicating that the person has died.
- Make it unambiguous that the person has died and that brainstem testing has confirmed this. For example:

> *I'm afraid I have very serious news.The results of the tests show that Áine has died.*

- Sometimes, the words "*dead*" and "*death*" are experienced as very blunt and can provoke extreme distress. It is acceptable to use less direct but still **unambiguous** terms, such as:[3]
  - *"passed away"*
  - *"has not survived"*
  - *"no longer alive"*

Providing information and planning

Delivering bad news

Repeat key information

- It can be helpful to repeat key information at the end of giving the news, especially the central point that the tests show the person has died. Repetition can support understanding when people are in shock.

Give the family time

- Give family members time to take in the news and time to respond.
- Maintain your attention towards them during this time – stay present, allow silence, and be available for questions or emotional reactions.

Providing information and planning

Delivering bad news

Offer condolences

- Offer sincere condolences and show recognition and validation of their feelings, without claiming to fully understand. For example:

> *I'm so sorry. This must be incredibly difficult to hear.*

- When it feels appropriate, and using your judgement about their readiness, reassure them that the deceased will continue to be treated with dignity and respect. For example:

> *Whatever happens next, please let us reassure you that [patient name] will be treated with dignity and respect at all times.*

Providing information and planning

Delivering bad news

Offer condolences *(Contd.)*

- Moving from the bad news to talking about the care that is being provided, and what concrete steps will happen next, can help transition into the next phase of the conversation.[12] For example:

> *So, the next thing that will happen is…*

TIP

A step-by-step approach to giving bad news does not usually make the conversation longer than moving straight to the news itself. It can save time and discomfort because it reduces the chance that family members will react so strongly to bluntly delivered news or sensitive topics that they become unable to participate in the conversation and then need a great deal of support and time before they can engage again in conversations and decisions.

Providing information and planning

Brainstem testing and death

Communication skills

- [ ] Warning shot
- [ ] Repeat the clinical story
- [ ] Explain brainstem testing
- [ ] Use easy-to-understand language
- [ ] Use pauses and silence
- [ ] Check understanding

Warning shot

- If it is now clear that the family members do not fully recognise that their loved one has died, broach this gently using skills that are known to support people to come to an understanding of bad news and to reduce the chances of severe distress, shock, and upset.
- Use a warning shot or wish statement to prepare them for the news. For example:

I'm afraid this isn't the news you were hoping for.

I wish we had better news to give you.

Providing information and planning

Brainstem testing and death

Repeat the clinical story

- Recap the clinical story in a way that leads naturally towards the explanation of brainstem testing. For example, you might refer to:
  - The severity of the brain injury
  - The fact that the patient has needed mechanical ventilation
  - The purpose and timing of the brainstem tests.

Explain brainstem testing

- Explain brainstem testing in clear, simple terms:
  - What the tests involved
  - What the results mean
  - That brainstem death means that the person has died, even if machines are still supporting breathing and circulation.
- Emphasise that brainstem death is established through a **series of tests**, not just one, and that these tests are carried out by **two different doctors**, in line with strict protocols.[5]

Providing information and planning

Brainstem testing and death

Use easy-to-understand language

- Avoid technical jargon. Use clear, straightforward language and provide honest, accurate information.[8]
- Avoid ambiguous terms that can be misunderstood, such as "*critically ill*" or "*very poor prognosis*", when you are conveying that the person has died.
- Make it clear that brainstem testing is used to determine whether the person is **dead**.
- For some people, words like "*dead*" and "*death*" can feel very blunt and may trigger intense distress that can derail the conversation. Balance clarity with sensitivity, using empathic tone and pacing. Experienced clinicians sometimes use indirect terms and phrases, provided they are still unambiguous. Examples include:[3]

has not survived

passed away

no longer alive

Providing information and planning

Brainstem testing and death

Use pauses and silence

- After you have explained that the brainstem tests show that the person has died, pause.
- Allow silence so that the news can sink in and so that emotional reactions have space to emerge.
- Offer sincere condolences and acknowledge how hard this is to hear, either during or after these pauses. For example:

Providing information and planning

Brainstem testing and death

Check understanding

- Check understanding regularly and invite questions:

> *Can I check what you have understood so far about the tests?*

> *Is there anything about what I've said that doesn't make sense?*

- Be ready to repeat the central points more than once, as people who are distressed or in shock may need information to be revisited several times before it is fully understood.

Providing information and planning

Organ and corneal donation

Communication skills

- [ ] Warning shot
- [ ] Link to patient's wishes and values
- [ ] Introduce the opt-out register
- [ ] Clarify who can decide
- [ ] Explain the donation process in simple steps
- [ ] Emphasise time, choice, and unchanged care

General principles

- Only raise organ or corneal donation **after** you are as confident as you can be that the family have understood that their loved one has died (or will not survive), and, where possible, **after a short break** in which they have had time with that news and with the patient.

Providing information and planning

Organ and corneal donation

General principles *(Contd.)*

- When introducing organ or corneal donation, keep the focus on what the patient would have wanted, rather than the preferences of the team or relatives alone.
- Emphasise that organ and corneal donation are **options**, not obligations, and that care and dignity are unchanged whatever is decided.

Warning shot – signalling a sensitive topic

- Before introducing organ or corneal donation, give a brief warning that you are moving to a sensitive subject. For example:

> *There is something important I would like to talk through with you. It's about what might happen next, and some families find it a difficult thing to think about.*

Providing information and planning

Organ and corneal donation

Warning shot – signalling a sensitive topic *(Contd.)*

I'm so sorry that you're having to make so many decisions at such a painful time. There is something else I need to raise with you, and it is entirely your choice.

- Pause and check that they feel able to continue:

Is it okay if we talk about that now?

Providing information and planning

Organ and corneal donation

Link to the patient's wishes and values

- When you first raise donation, link it explicitly to the way the person has died and to their possible wishes or values. For example:

> *Because of the way that [patient name] has died, there may be an opportunity for them to help other people by donating organs or corneas.*

> *You're the people who knew [patient] best, so we would like to understand from you what might fit with who they were and what mattered to them.*

Providing information and planning

Organ and corneal donation

Link to the patient's wishes and values *(Contd.)*

- Explore, without pressure, whether they have any sense of the patient's wishes:

> *Many families haven't talked about organ donation before, and that's completely normal. Thinking about [patient] and what mattered to them, do you have any sense of how they might have felt about donation?*

- Attend carefully to values, beliefs, and any relevant cultural or religious considerations. Reflect these back to show you have heard them.

Providing information and planning

Organ and corneal donation

Introduce the opt-out register

- Explain the opt-out register briefly and in a way that keeps the focus on the person. Refer to the register in a neutral, supportive way, keeping the focus on the person's values and the family's understanding of their wishes. For example:

> *In Ireland, there is now an opt-out system for organ donation. There is a national register for people who have chosen not to donate. Not everyone knows about the register, so we do not assume it tells the whole story. Our role is to help you think about what Áine would have wanted, within what the law allows.*

> *We have checked the opt-out register, and [patient name] is/is not on it.*

Providing information and planning

Organ and corneal donation

Clarify who can decide

- Before discussing donation in detail, clarify who you must look to as the main person to guide you, in line with local law and policy (for example, a statutory hierarchy of "*designated family members*").
- Explain this in simple terms and keep the focus on the patient's wishes:

> *The law here sets out an order of who we should speak to first if the person hasn't formally appointed someone themselves. In that list, [e.g. a spouse or cohabiting partner] comes before [e.g. parents or siblings].*

> *In [patient]'s case, because they were living with you as their partner, you are the person we must look to as their main decision-maker about donation.*

Providing information and planning

Organ and corneal donation

Clarify who can decide *(Contd.)*

- Acknowledge that other family members' views and feelings are important:

> *All family members' views are important - we want to hear from everyone. But if there isn't agreement, the law says we have to be guided by you.*

- Centre the decision on what the patient would have wanted, not on family conflict or staff preferences:

> *Our role is to help you think about what [patient] would have wanted, within what the law allows.*

Providing information and planning

Organ and corneal donation

Explain the donation process in simple steps

- If the family are open to hearing more, give a brief, stepwise explanation of what donation would involve, using clear, non-technical language. For example:

Further checks and coordination

If you decide that donation is right for [patient], our specialist team would do further checks – blood tests and a review of their medical history – to see whether and which organs or corneas might be suitable.

We would also coordinate with the national transplant service to identify people who could benefit.

Ongoing care before the operation

Until the time of the operation, [patient] would stay here. We would continue to care for them, keeping them comfortable and maintaining organ function. You would still be able to spend time at the bedside, talk to them, and say your goodbyes in the way that feels right to you.

Providing information and planning

Organ and corneal donation

Explain the donation process in simple steps *(Contd.)*

The operation itself

When everything is ready, [patient] would be taken to the operating theatre. The operation to remove organs or corneas is carried out by highly trained surgeons, in a similar way to other major operations.

Only the organs or corneas that have been agreed would be removed.

After the operation

Afterwards, [patient]'s body would be carefully cared for and prepared, and then returned to you or to the funeral director, depending on the arrangements you choose.

You would still be able to have an open-casket funeral if that is part of your tradition – the surgical incisions are covered and not visible under normal clothing.

Providing information and planning

Organ and corneal donation

Explain the donation process in simple steps *(Contd.)*

- Address common worries in clear, honest language:

– Funeral arrangements:

> *You would still be able to have an open-casket funeral if that is part of your tradition – the surgical incisions are covered and not visible under normal clothing.*

– Pain and awareness:

> *Because Áine's brain has died, she has no awareness and no ability to feel pain or discomfort.*

– On respect and dignity:

> *If organ donation goes ahead, the surgical team will treat Áine with the same respect and care as any patient having an operation.*

Providing information and planning

Organ and corneal donation

Support decision-making: time, choice, and unchanged care

- Make it explicit that there is **no right or wrong answer**, only what most closely reflects the patient's wishes and what the family can live with:

> *Whatever you decide, there is no single 'right' or 'wrong' decision. The most important thing is that it feels as true as possible to Áine's values and wishes.*

- Acknowledge time constraints honestly, without rushing or pressuring:

> *There is some time pressure, because if donation is going to help other people it needs to happen within a certain number of hours. You can take some time together now, and we can come back to talk again a little later.*

Providing information and planning

Organ and corneal donation

Support decision-making: time, choice, and unchanged care *(Contd.)*

- Emphasise that donation is voluntary and that care is unchanged whatever they decide:

> *This is entirely your choice. We will continue to care for [patient], and for all of you, with the same respect and support, whatever you decide.*

- Offer time and space for them to talk alone and agree on when you will return:

> *Would you like some time on your own now to talk about this? If so, we can agree a time for us to come back and see how you're feeling about it.*

- If a decision is made, summarise it and outline next steps (linking to section 6 on closing conversations and documentation).

Providing information and planning

Organ and corneal donation

TIP

When time is limited, prioritise:

- A brief warning shot
- One or two key empathic statements
- A short gathering question (e.g. "*Please tell me how you understand what's happening?*")
- A simple structure (e.g. *"There are two things we need to talk about…*"), and
- A clear plan to return:

> *We only have a few minutes now, but I will come back at [time] so we can talk more and answer your questions.*

Closing the conversation

Aim

To bring the conversation to a clear, respectful close, ensuring that key points are understood, next steps are clear, and support is emphasised.

Communication skills

- [ ] Summarise key points
- [ ] Check understanding and invite questions
- [ ] Clarify next steps
- [ ] Agree follow-up
- [ ] Appreciation and condolences
- [ ] Document the conversation

Summarise key points

- Offer a brief, clear summary of the main things you have discussed:

> *We've talked about what the tests show about Áine's condition, that the tests mean she has died, and we've started to discuss the possibility of organ donation and what that could involve.*

Closing the conversation

Check understanding and invite questions

I know that's a lot of information to take in. What feels most important to you right now, and what you would like us to do next?

Is there anything you'd like me to go over again?

Clarify next steps

- Explain **what will happen next, when, and who will be involved:**

I will come back to you by [time] to see how you are and whether you've been able to think more about the decision.

Over the next few hours, we will…

Closing the conversation

Clarify next steps *(Contd.)*

- Emphasise that the patient will continue to receive the **best possible care** and will be treated with **dignity and respect**, whatever decision is made:

> *Whatever you decide, Áine will continue to be treated with dignity and respect at all times.*

Agree follow-up

- If a decision has not yet been made, agree on a clear time for follow-up and what that will cover (e.g. revisiting questions, clarifying decisions, checking on how they are coping).

Closing the conversation

Appreciation and condolences

- Thank them for their time and the effort of engaging in such a difficult conversation:

> *Thank you for talking with us about this in such an incredibly difficult time.*

- Offer sincere condolences again.

Document the conversation

After the discussion, record the conversation in the healthcare record, in line with local policies. Include:

- Who was present.
- The key information given.
- Questions asked and how they were addressed.
- Any decisions made or deferred.
- The agreed follow-up plan (time, who will attend, and what will be revisited).

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